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Version: Version of Record

Link(s) to article on publisher's website:

<http://dx.doi.org/doi:10.21954/ou.ro.0000e2a0>

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Katie Bourne BSc Hons

**DETERMINING CAPACITY TO CONSENT IN PEOPLE WITH
LEARNING DISABILITIES**

A thesis submitted as partial fulfilment of the requirements of the Open University for the degree
of Doctor of Clinical Psychology

21st July 2000

20,000 Words

**SALOMONS
CANTERBURY CHRIST CHURCH UNIVERSITY COLLEGE**

AWARD DATE: 20 September

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ACKNOWLEDGEMENTS

I would like to thank the participants who offered their time and commitment to the project. Thank you for sharing your experience and views with me. My thanks also goes to the services who gave their permission and support to my study.

A huge thanks to my supervisor, Anthea Sperlinger. Thank you for your time, guidance and most of all thank you for your belief in me. I would also like to thank Gary Brown whose feedback was invaluable, and Jan Burns, Tony Lavender and Katy Arscott for helpful discussion when my ideas and the design of the study were in their early stages.

Finally, I want to thank John for keeping the promise he made.



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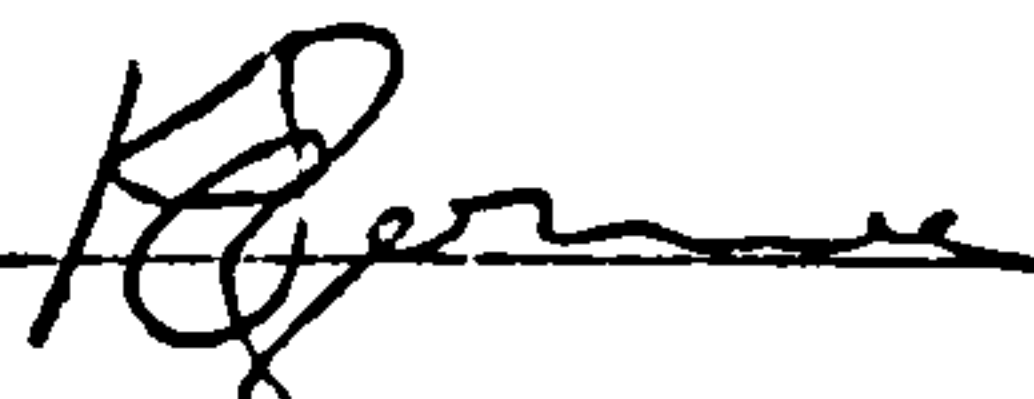
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Implications: The study's findings provided a vast amount of information related to the assessment of capacity to consent to treatment and capacity to consent to a sexual relationship. This builds on our understanding of how current ideas which have arisen out of the literature in this area, relate to the assessment of competency in practice. Thus in essence the findings of this study provided an in-depth exploration of the assessment of capacity from the perspective of the professional, expanding on our knowledge in this area as well as identifying areas in need of further exploration.

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1. INTRODUCTION

1.1 Capacity to consent: people with learning disabilities

1.1.1 Historical overview

The issue of competence has long been debated in the field of learning disabilities where historically adults have not been seen to have the capacity to make decisions affecting their own lives (Fennell, 1996). Therefore, decisions such as those related to medical treatment have been made for people with learning disabilities and in some cases this has led to treatment against the individual's will, one example being sterilisation (Murphy & Clare, 1997). This assumption has also historically meant that those who care for people with learning disabilities have controlled most aspects of their lives. One obvious example here is the right to personal or sexual relationships. In this population, sexual intimacy has been believed to be inappropriate and strongly discouraged. For example, in the past wards may have been segregated by sex and no contraceptive or sexual advice offered (Murphy & Clare, 1995). The belief that people with learning disabilities are unable to make decisions regarding their own lives essentially means their rights become disregarded.

With the introduction of normalisation these views have been radically challenged (Nirje, 1980; Wolfensberger, 1980, 1983; Emerson, 1992). This has led to more emphasis being placed on age appropriate, culturally normative experiences and with the move towards community living (Mansell, 1997) the opportunities and scope for decision-making have also increased. In essence, it is now argued to be unacceptable to assume that adults with learning disabilities do not have the capacity to make decisions affecting their own lives (Law Commission, 1995). This is reflected in current law which states that all adults have the right to make decisions affecting their

lives unless there is evidence to the contrary and should be encouraged and enabled to do so (The Law Commission, 1995). However, whilst views have changed, personal choice continues to be limited for some people with learning disabilities (MENCAP, 1989). For example, simple choices are made according to the preferences of carers and in some organisations decisions that are more serious may continue to be deemed beyond the capacity of people with learning disabilities (Curran & Hollins, 1994). Individuals with learning disabilities should be viewed as the best authority on their own lives (Goodley, 1996). Honouring the competent individual's decision fosters respect for that person (Federal Register, 1979).

1.1.2 Focus for this research

Difficulties involving thought, affect and cognition which are associated with the problems experienced by people with learning disabilities seem likely to impair the abilities required for autonomous decision-making and thus assessment of capacity is particularly salient in services for people with learning disabilities (Wong, Clare, Gunn & Holland, 1999). Professionals are now more likely to be asked to address issues related to competency and hence assessment of capacity has become the focus of considerable attention. The assessment of the presence or absence of capacity in people with learning disabilities has major implications for choice, self-determination and protection from harm and thus raises complex questions for the health care professionals upon whom people with learning disabilities are dependent.

In practice there are any number of decisions that may be made where mental capacity is central (BMA/LS, 1995). For example, capacity to deal with financial situations, make a will, to litigate, to enter into a contract, to vote, to enter sexual relationships and to consent or refuse medical treatment. The most common decisions on which advice is sought are capacity to consent to treatment and capacity to consent to sexual relationships (Murphy & Clare, 1997). These

decisions and the way in which professionals working with people with learning disabilities approach them are thus the focus for this research.

The literature with regard to assessing capacity to consent to treatment and to sexual relationships and the guidance it provides for professionals is however limited. The research that has been done in this area appears to have developed out of the legal literature on the assessment of competency and thus our current understanding of competency is heavily dependent on legal findings. Reviews of this area with regard to people with learning disabilities are limited to a small number of comprehensive articles (e.g. Murphy & Clare, 1995; BMA/LS, 1995; Arscott, 1997; Wong et al. 1999). The research being done related to competency appears to be focused on approaches to assessing capacity with some emphasis on the development of tools for doing this. A review of this literature and the findings of current research are outlined below.

Assessing capacity is a complex task and at present little is known about how current ideas which have arisen out of the literature with regards to competency relate to practice. Little is known about how decisions about capacity are approached by professionals, although some have speculated about the difficulties that this might present (e.g. Sinclair, 1997; Arscott, 1997; Glass, 1997). Professional decision-making is thus discussed in the review below with regards to the assessment of capacity. Lastly, the study, its design, rationale and the research questions asked are outlined.

1.2 What is meant by capacity to consent?

1.2.1 Understanding capacity to consent

In legal contexts, capacity to consent is defined as the ability of a person to make legally significant decisions about him or herself. Once a person has reached adulthood they are assumed to have legal capacity unless there is evidence to the contrary (BMA/LS, 1995). The concept of capacity has evolved to include the concept of informed consent. Consent is the mechanism through which autonomy is exercised (Sprung & Winick, 1989). In the United States, ‘informed consent’ is argued to have three main components (Appelbaum & Grisso, 1988). These components are: possessing sufficient information relevant to the decision being made, having the capacity to make that decision and to understand the consequences, and making the decision voluntarily free from coercion. Capacity must therefore be assessed before informed consent can be sought (White, 1994). These two concepts are pivotal in balancing the right to self-determination and the freedom to make one’s own decisions, with the right to protection from harm (Kaplan, Strang & Ahmed, 1988).

The piecemeal legal provision and the lack of universally accepted standards in relation to capacity (Law Commission 1991; Murphy & Clare, 1995; Venesey, 1994) led to an inquiry and report by the Law Commission of England and Wales (1995). In this report being without capacity to make a decision is defined as ‘unable by reason of mental disability to make a decision on the matter in question’ or ‘unable to communicate a decision on that matter because he or she is unconscious or for any other reason’. In the report the ‘inability to make a decision’ means ‘an inability to understand or retain the information relevant to the decision, including information about the reasonably foreseeable consequences of deciding one way or another or of failing to make the decision’ or ‘an inability to make that decision based on that information’. A

person may be deemed without capacity because of a lifelong mental disability, capacity may be attained and then lost through trauma or the onset of a degenerative disease, or may fluctuate because of temporary factors such as illness, unconsciousness, confusion or the effects of fatigue (Wong et al. 1999).

1.2.2 Capacity to consent to treatment

Current legal definitions of capacity to consent to treatment can be found in case law and in The Mental Health Act Code of Practice (Department of Health and Welsh Office, 1993, para. 15.10). In case law the current accepted test of capacity requires an individual to; 1) sufficiently understand the nature, purpose and effects of a proposed treatment and retain the treatment information; 2) believe it; and 3) assess the information in arriving at a choice. The right to self-determination exists regardless of the outcome of the decision or the diagnostic group to which the patient may belong (Wong, 1997). The MHA code of practice suggests that to be able to consent an individual must possess an 'adequate knowledge of the purpose, nature, likely effects and risks of (the) treatment including the likelihood of its success and any alternatives to it' (p.55). However, this only applies to people with a mental disorder as defined by the Act and it is unclear what criteria should be used to assess 'adequate' knowledge.

Health care professionals cannot legally examine or treat any person without his/her valid consent (BMA/LS, 1995) and this consent must be provided by the person being treated (Murphy & Clare, 1995). This right to autonomy exists whether the reasons for making the choice are rational, irrational, unknown or even non-existent (BMA/LS, 1995). The right to self-determination is only seen as meaningful if the person is appropriately informed, is free to make decisions from coercion and has the ability or capacity to do so (Wong et al. 1999). The

exception here is if the person is being treated under the provisions of Part IV of the Mental Health Act (1983).

Where a person is seen as unable to consent, treatment may only be given in exceptional circumstances involving either necessity (the meaning of which is unclear, Mackay, 1990) or an emergency. This may mean that people with learning disabilities do not receive the treatment they require because of uncertainties about its lawfulness (MENCAP, 1989). However, The House of Lords (1990), in a more recent ruling stated that those providing treatment for someone unable to give consent would not be subject to accusations of unlawful actions provided that they acted in the person's best interests and in accordance with a responsible and competent body of relevant professional opinion (Murphy & Clare, 1995). Thus, when acting in terms of the client's best interests professionals should consider the least restrictive means of supporting that client.

1.2.3 Capacity to enter sexual relationships

In England and Wales, a sexual relationship between two people is lawful if both partners are able to consent and have given their consent (Gunn, 1996). In law women aged 16 years and above are seen as able to consent to a heterosexual or homosexual relationship. For men entering a heterosexual relationship there is no lower age of consent. Whilst for men entering a homosexual relationship only those aged 16 years and above are deemed able to give consent. With few exceptions, people can consent to sexual activity and therefore rights must not be infringed upon (BMA/LS, 1995). The law only becomes involved where there is concern that the person did not consent, hence questions are not raised about capacity but incapacity.

The focus of current law is on protection from abusive relationships (BMA/LS, 1995). Where there is sexual activity and consent is disputed a sexual offence may have taken place. Whilst a

professional may be asked whether a person could have given their consent (i.e. 'did they have the capacity to make the decision?'), whether or not they did give their consent in the situation in question is a matter for the court to decide (Murphy & Clare, 1997). This focus on protection from abuse and exploitation is also often reflected in local service guidelines (Booth & Booth, 1992). In such guidelines although it is frequently asserted that people with learning disabilities have an equal right to sexual expression, guidance is mainly offered on what should be done if abuse becomes known, whilst little help with regards to what constitutes consent is given (Murphy & Clare, 1995).

Entering a sexual relationship does not require any formal test of capacity (BMA/LS, 1995). Decisions regarding sexual relationships must be taken by service users personally. They are not within the decision-making powers of carers (Law Commission, 1993) and nobody can be told to have a sexual relationship. The reason why consent is given is also not considered relevant in law, thus enabling people to consent for all sorts of reasons. People may therefore consent for reasons that include sexual gratification, affection, duty, money, physical closeness, physical comfort or fear (Murphy & Clare, 1995). Exactly what constitutes 'consent' to sexual activity is thus unclear. There is no requirement that people engaged in sexual activity should exercise informed consent of the kind required for medical treatment. There is thus no requirement under law that people demonstrate that they understand the nature of sexual activity, the risks, benefits or the alternatives to sexual activity.

However, in common law the test of capacity to consent to sexual relations implies that the person understands what is proposed, its implications and is able to make a free choice (BMA/LS, 1995). Strictly applied this means that a person needs to have good sexual knowledge and good social and communication skills. In practice where a sexual relationship involving a

person with a learning disability has begun or appears likely, Murphy and Clare (1995) suggest carers and professionals should consider the following issues; 1) Is there a major imbalance of power between the two individuals and if so is there a greater risk of an abusive relationship? 2) Is the sexual relationship rewarding in itself or is one person offering the other inducements? 3) If the relationship is heterosexual, do both partners realise that pregnancy can result? 4) If the relationship is heterosexual, do both partners know what contraception is and how to use it? 5) Do both partners understand the risk of sexually transmitted diseases and know how to engage in safer sex? and 6) if pregnancy is possible have both partners been given adequate access to genetic counselling and been informed and understood issues related to parenting?

Where it is difficult to be sure that a client's consent is valid, health care workers should look to see whether the two people seek each other out, spend time together, share leisure activities and restrict activities with other people (Murphy & Clare, 1995). If two people are not able to understand sex education, then informed consent may not be possible. However, some people would still argue that people have a right to be sexual (Brown & Craft, 1994) if they appear to have a genuine affection for one another and there is no exploitation involved. This can be a difficult decision for all those involved.

1.3 Approaches to assessing capacity to consent

It is a major challenge to set a threshold which is neither too low so as not to provide adequate protection from harm nor too high so as to restrict freedom of choice (Wong et al. 1999). Much consideration has been given to approaches that might be used to assess capacity to consent from which three broad approaches can be distinguished. These are:

1.3.1 The diagnostic or status approach

This approach bases an individual's capacity on his/her membership to a specific group or population e.g. people with a learning disability, dementia or a mental disorder. Assumptions are made about the individual's ability to make decisions based on specific characteristics related to their diagnoses or status. That is, being deemed a person with a learning disability automatically means they do not have the capacity to consent.

Whilst this approach is simple and easy to apply it is generally regarded as inappropriate, subjective (Appelbaum, Lidz & Meisel, 1987) and too blunt (Jackson, 1994). Lack of capacity cannot be presumed because someone carries a specific label (Gunn, 1994). This approach assumes that a group sharing a particular characteristic is homogenous and that all decisions place similar levels of demand upon the decision-maker. Neither of these assumptions have been supported empirically (e.g. Morris, Niederbuhl & Mahr, 1993; Grisso & Appelbaum, 1995). In England and Wales the status approach has been rejected in both case law and by the Mental Health Act Code of Practice (Department of Health and Welsh Office, 1993).

1.3.2 The outcome approach

This approach uses the person's decision as the criterion on which assessment of capacity to consent is based. That is, it measures an individual's capacity to make decisions about treatment in relation to the consequences of their decision (Law Commission, 1991; Stanley, 1987; Venesky, 1994). Therefore, an individual who makes a decision that is contrary to conventional wisdom or is seen as unreasonable by the treatment provider, will be seen as without capacity (Wong et al. 1999). A sliding scale has been proposed to implement the outcome approach (Drane, 1984). This model classifies treatment decisions into three standards. These standards outline the conditions under which health professionals may prevent an individual's decision being allowed.

Assessment of competence becomes more stringent as the likely risks become more serious (Arscott, 1997).

Whilst this approach allows professionals to protect people from negative consequences (Hoggett, 1994) it is argued by Culver and Gert (1990) not to be a scale of competence but a scale of a professional's view as to when an individual's decision should be accepted or when it should not. This undermines an individual rights, negates the role of letting a competent person decide whatever they want and is biased in favour of decisions to accept treatment (Arscott, 1997). The approach is also potentially inconsistent across individuals and between assessors (Venesy, 1994). Again this approach has been firmly rejected in case law (Kennedy & Grub, 1994).

1.3.3 The functional approach

The functional approach is the most frequently applied by current English law and has attracted the most informed support (President's Commission, 1983; Law Commission, 1995; Scottish Law Commission, 1995; Wong, Clare, Holland, Watson & Gunn, 2000). It is based on establishing an individual's understanding, knowledge, beliefs, skills and abilities and the extent to which these abilities match the demands of the decision-making task (Grisso, 1986; Wong et al. 2000). Capacity is not viewed as permanent or global but fluctuating (Wong, 1997). A person's abilities should therefore be assessed with specific regard to the demands of a particular situation and particular decision (Dimond, 1993; Grisso & Appelbaum, 1998; Marson, Schmitt, Ingram & Harrell, 1994; Searight, 1992; White, 1994).

Whilst this approach is time consuming as it must be applied to each decision, each time it is made (Hoggett, 1994), it allows a better balance between the values of autonomy and protection

because people can be deemed capable of some decisions and not others (Arscott, 1997). Consideration needs to be given to improving a person's capacity through education (Chaplin & Kent, 1998), treating an underlying disorder (Grisso & Appelbaum, 1995) or simplifying the task to aid processing of the information (Grisso & Appelbaum, 1995).

There has been much academic interest regarding which functional abilities are relevant to making treatment decisions (Roth, Miesel & Lidz, 1977; Presidents Commission, 1993; Law Commission, 1995; Gunn, 1994). However, there is no unanimous agreement on the abilities that constitute capacity or how these should be assessed (Grisso, 1986; Gunn, 1994; Wong, 1997). The criteria used are often vague and rely on unobservable mental processes as opposed to concrete and observable elements of behaviour (Arscott, 1997). Further to this, many of the criteria rely heavily on a number of abilities including verbal skills, memory for words or phrases and attentional processes, therefore biasing determinants of competence against those who experience difficulties in these areas (Appelbaum & Grisso, 1988).

1.3.4 An integrative approach

It has been suggested that these approaches could be usefully integrated when assessing capacity to consent (Arscott, 1997; Wong et al. 1999). For example, combining the outcome and functional approaches using a sliding scale model, where a functional assessment would only be initiated if the decision is considered complex or the risk involved in accepting or refusing treatment is considered great (Jackson, 1994; Roth, et al. 1977). However, this approach may miss the point (Gunn, 1994) because both the desirability and dangerousness of the outcome are determined by a professional, therefore negating the client's own abilities and values (Wong et al. 1999). Alternatively, a combination of the functional and diagnostic approaches has been suggested. The functional approach would only be applied when, because of the individual's

status their capacity has come into question (Appelbaum et al. 1987; Hoggett, 1994; Law Commission, 1995). Although there is some controversy concerning this approach (Carson, 1993) because it could prejudice against people with a disability, this is the combination of approaches currently proposed (Law Commission, 1995; Scottish Law Commission, 1995).

1.4 Assessing capacity to consent in practice

1.4.1 Psychological tests of capacity to consent - treatment

Whilst there have been few psychological tests developed for assessing capacity in practice and rarely for use with people with learning disabilities, those that are available have been developed from a functional perspective and with regard to consent to medical treatment. There is no universal agreement on which functional abilities contribute to the assessment of capacity, although there is a consensus that the following abilities are important. These are: 1) the ability to communicate a choice; 2) understanding the relevant information; 3) retaining the information; 4) appreciating its relevance to oneself and; 5) being able to weigh up the risks and benefits and rationally manipulate the information to arrive at a choice (Appelbaum & Grisso, 1988; Weisstub, 1990; Law Commission, 1995; Wong et al. 2000). These tests are in essence standards of competence, allowing autonomy to be maintained or forfeited (Kaplan et al. 1988).

A number of tests have been developed for use in clinical practice with people with mental health problems and people with dementia (e.g. Appelbaum & Grisso, 1995). Tests to be used with people with learning disabilities are in general lacking. Morris et al. (1993) developed the first test of capacity to consent specifically for use with people with learning disabilities. However, this was developed as a research tool rather than for use in clinical practice. The test is based on three vignettes related to treatment, which require informed consent. In each vignette the

underlying problem and a description and review of the proposed treatment is presented to the client, followed by a series of questions to test the individual's ability to consent to that treatment. The measure is argued to be unnecessarily stringent and does not take into account the difficulties experienced by clients when faced with treatment decisions. Thus people who may be able to make decisions for themselves would not be considered able to do so if this test were applied (Arscott, 1997). When Arscott, Dagnan & Stenfert (1999) attempted to simplify this measure with the aim of making it easier for people to understand the information presented, it increased the number of people able to give consent. However, as Arscott et al. (1999) point out, measuring the validity of this test is made difficult by the lack of standardised measures of competence. Thus, whilst it is unlikely that tests will be used as the sole predictor of competence in people with learning disabilities, they are seen as providing useful guidance for professionals (Arscott et al. 1999). Given the difficulties there are in assessing capacity to consent to treatment, Wong et al. (1999) propose a framework in the format of a decision-making tree to assist professionals in the process of making such assessments.

1.4.2 Tests of capacity – sexual relationships

A number of sex education training packages are available for working with people with learning disabilities (Craft & Brown, 1994). There are also a number of tests of sexual knowledge, some of which include social interaction questions as well as questions about sexual facts (e.g. Fisher, Krajicek & Borthick, 1973; Wish, McCombs & Edmonson, 1979; Bender, Aitman, Biggs & Haug, 1993). However, there are no specific assessments of capacity to consent for use in these circumstances.

1.4.3 Factors affecting the assessment of competence

Consideration has also been given to the factors that may affect the assessment of competence in people with learning disabilities. There are a number of individual and environmental factors which need to be taken into account when assessing the capacity to consent of a person with learning disabilities as they affect the ease with which information will be understood (Kent, 1994; Murphy & Clare, 1995; Sprung & Winick, 1989; Venesy, 1995). Individual factors for example include; general cognitive ability, verbal expression and understanding, memory capacity, the speed with which information is assimilated and personal values (Appelbaum et al. 1987; Murphy & Clare, 1995; Venesy, 1995). Acquiescence and compliance are likely to be higher in this population (Clare & Gudjonsson, 1993). People in this group are also likely to be inexperienced in expressing their own views and opinions and are more likely to feel unable to refuse (Arscott, 1997). Such individual differences are likely to be exacerbated by the environment in which consent is obtained. For example, the way in which information is presented and elicited from clients (Appelbaum & Roth, 1982; Murphy & Clare, 1995) can all influence the understanding and processing of information.

1.5 Professional decision-making

1.5.1 Assessing capacity to consent in practice

In practice it is argued that health care professionals, social workers and carers are often ill-informed about issues related to assessing capacity to consent (Sinclair, 1997). The lack of knowledge and guidance often means that decisions are made for people with learning disabilities without properly assessing their competence. There are still assumptions that the label learning disability automatically removes the person's ability to consent. Whilst capacity to consent maybe a one off judgement which is rarely reviewed and denies the person any chance of self-

determination (Sinclair, 1997). Sinclair (1997) believes that whilst the diagnostic approach is rarely used today, it still has a residual effect on the thinking of some professionals. Sinclair (1997) also argues that many professionals will use the outcome approach, consciously or not. Arscott (1997) questions whether we as professionals are willing to accept the decision of an individual deemed competent, if the decision they are making is not in their best interests. The question of competency thus raises many ethical and professional dilemmas (Arscott, 1997), the approach taken by professionals in practice being unclear.

1.5.2 Legal versus social constructs of competency

Glass (1997) argues that competence is a social construct influenced by the values of society and the professional completing the assessment. There is much diversity and depth to the decisions professionals are asked to make. Reliable measures of competence are found wanting because they cannot accommodate the issue of judgement (Elliott, 1991). Boundaries, whether social, psychological or legal, do not exist naturally and are constructed by people in both formal and informal ways. Competency is a construct that is designed to either empower or restrict the rights of people for particular purposes. The attitudes of those who provide direct care are particularly important because it is their feelings, behaviours and agendas which often create an informal policy that seriously affects the rights of people with learning disabilities (Bratlinger, 1983). The construct will thus vary within settings and will be influenced by those engaging in this process (Glass, 1997). Glass (1997) argues that whilst it may not be possible to eliminate the influence of values held, their impact should be made explicit so that we may judge openly whether they are legitimate.

When health care professionals interact with the legal system, there is a danger that the uncertainties of the clinical perspective will be abandoned for the rationality of legal thought

(Appelbaum & Roth, 1982). The law has tried to address competency as though it were a fixed attribute with an inherent stability. What the law calls competency is in fact a set of deductions from a variety of clinical data that can be subject to influence and change as the more basic mental attributes on which it is based. The clinician must thus continue to think clinically about the problem before them. Again, the perspective of the professional and their approach to the assessment of competency in clinical situations is essential to developing a complete understanding of competency and the many difficulties its determination raises.

1.5.3 Ethical dilemmas in the assessment of competency

Wear and Brahams (1991) argue that by and large health care professionals are more likely to be guided in their decision-making by conscience, that is what seems to be the right course of action rather than legal constraints. Thus in establishing competence there can be a number of conflicting moral principles which Wear and Brahams (1991) categorise into four moral perspectives. 1) Rights theory: this rests on the belief that all people have rights but these conflict when, for example, treatment is refused although it is viewed as needed. Overruling rights rests on establishing the person's competence or incompetence. 2) Virtue theory: this rests on being fair, making a just decision. The conflict here arises because being fair might not be doing good. 3) Common-sense morality: this refers to the moral perspective with which we have been brought up and thus the view that it is wrong to go against a person's wishes. Here again the issue of competence arises. Finally, 4) utilitarianism: this stresses outcome and the person's welfare. For example, in the case of treatment, causing discomfort or pain is outweighed by the increased welfare to the patient. However, in defining welfare one aspect of this might be the right to be able to choose. Thus, it appears important when thinking about professional decision-making to take into account ethical considerations that might be affecting this process.

Further consideration of the factors affecting professional decision-making could include a look at the literature on decision-making theory. This looks at how individuals attempt to reduce uncertainty, how they come to understand and arrive at a decision and how cognitive, emotional, behavioural as well as biological and social factors influence the decision-making process. However, unfortunately consideration of this literature is beyond the scope of this review.

1.6 The study

1.6.1 Rationale for the research

Assessing an individual's capacity to consent involves balancing the two often-contradictory positions of enhancing self-determination and at the same time ensuring protection from harm (Morris et al. 1993). Balancing these two view points can be difficult and yet to date there has been no exploration of how professionals assess capacity to consent or how the law or the approaches mentioned relate to or are reflected in decision-making in practice (Hoggett, 1994).

Gaining further insight into the process of assessing competence from the view of the professional, a perspective currently missing from the literature, has the potential to expand on the current knowledge base available in this area, as well as being immensely important in terms of client welfare.

1.6.2 Rationale for the methodology used

The present research aims to provide an in-depth description and exploration of the way in which professionals assess capacity to consent. Whilst there is considerable literature looking at capacity to consent in theory, there appears to be limited information with regards to the assessment of competency from the perspective of the professional, which in itself would appear

to be a complex process. Therefore, in the absence of previous research from this perspective the aim of the research was discovery orientated. Given the need to explore this process in-depth, a qualitative rather than quantitative methodology was perceived as most appropriate.

The methodology chosen also reflected the need to avoid predetermined assumptions about what the central issues for professionals are in assessing capacity to consent. Thus, the use of a qualitative approach aimed at discovery, was considered more appropriate than a quantitative approach based on hypothesis testing of pre-existing assumptions. In line with this, the use of individual interviews allowed participants' own understanding of capacity to consent to be heard, a perspective currently missing from the available literature.

Interpretative phenomenological analysis (IPA) was chosen to analyse the data as it seemed to best meet the study's aims. IPA aims to explore in detail the participant's view of the topic under investigation (Smith, Jarman & Osborn, 1999). It recognises that completing research is a dynamic process. IPA is an attempt to get closer to the participant's personal world, thus it is phenomenological in that it is concerned with exploring the person's personal perception or account as opposed to producing an objective statement of an object or event (Smith et al. 1999). It is interpretative in that in trying to obtain a participant's personal view the researcher must try to make sense of it through interpretation. Hence accessing personal perceptions depends on the researcher's interpretations (Smith et al. 1999). IPA allows the researcher to look at each individual participant's understanding, before moving to a group level of analysis.

IPA is amenable to the researcher starting from an informed position. Thus, given the available research from perspectives other than that of the professional, this seemed more appropriate than for example, using a grounded theory approach used when there is no available research to guide

analysis, the researcher thus starting from a position of not knowing. Smith et al. (1999) write that IPA differs from discourse analysis in the perception of the status of cognition i.e. discourse analysis is sceptical of mapping verbal reports onto underlying cognitions, being concerned with what the person is saying and the discourse they are using. Again, with regards to the aims of this research, using IPA appeared more appropriate than discourse analysis given the emphasis on meaning to the participant of the topic, rather than for example the social impact or purpose of the speech used by participants.

1.6.3 Guiding propositions

Elloitt, Fischer and Rennie (1999) emphasis the importance in qualitative research of making clear the researcher's views and assumptions. My clinical work with people with learning disabilities both direct and indirect (i.e. with carers, other professionals and services), as well my awareness of the literature in this area, has led me to the following assumptions and ideas regarding the assessment of capacity to consent in people with learning disabilities, by professionals:

- a) The concept of competence and hence the rights of people with learning disabilities to make decisions for themselves is not regularly considered in professional day to day practice.
- b) Assessment of capacity to consent is only undertaken when a client is seen to be refusing something of benefit or doing something not of benefit to themselves.
- c) The understanding of capacity to consent in services is fragmented thus making its application problematic.
- d) The view of capacity to consent or competency outlined in the literature and the law is simplistic and does not reflect the complexities of practice.

1.6.4 Aims and objectives

The aim of the study is to explore how capacity to consent in people with learning disabilities is determined by professionals in practice. To look at both the criteria upon which capacity is based and the factors affecting the decision-making process with regards to capacity to consent to treatment and capacity to consent to a sexual relationship. Secondary to this, the study aims to explore whether decisions made relating to capacity are made differently by different professional groups i.e. psychiatrists, psychologists, community nurses and care managers.

1.6.5 Research questions

- 1) In practice, what criteria do professionals use to assess capacity to consent to treatment in people with learning disabilities?
- 2) Are the criteria used by professionals to assess capacity to consent to a medical intervention, similar or different from those used to assess capacity to consent to a sexual relationship?
- 3) What factors affect the decision-making process when assessing capacity to consent?
- 4) Are decisions relating to capacity to consent, made differently by different professional groups?

2. METHODOLOGY

2.1 Design

A cross sectional design was utilised to gain the views of psychiatrists, psychologists, care managers and nurses. The data collected from individual interviews was analysed using IPA.

2.2 Participants

2.2.1 Recruitment

Participants were recruited from staff working with people with learning disabilities in two local NHS Trusts and one Social Services Department. Permission to approach staff was initially obtained from the respective service managers either verbally or in writing (appendix 1.). Recruiting participants from a number of different services was seen as important in terms of increasing the independence of the study's findings from the possible contextual influences on the views of participants when assessing competence.

2.2.2 Sampling issues

Participants were selected on the basis that given their professional experience they could expand on our current understanding of the issue being studied, thus applying the idea of theoretical sampling in line with the study's qualitative design. Given that qualitative research is concerned with the exploration of understanding and meanings, an attempt was made by interviewing a large number of participants from different professions to sample widely the possible range of views on this topic. Thus, the approach to sampling in qualitative research differs from that adopted in quantitative research which has different needs and aims to ensure representativeness and generalisability of findings through sampling.

Obtaining the viewpoint of the professionals most often involved in the process of assessing capacity was seen as important to the meaningfulness of the data collected given that the study was designed to explore how competency is assessed in clinical practice. Each profession comes from a different position, bringing a different perspective seen to be of value to addressing the research questions. Therefore, the views of a number of different professional groups was perceived as most likely to give a representative or naturalistic view of how this issue is addressed in clinical practice.

2.2.3 Selection criteria

Professionals with at least a year's post qualification experience of working with adults with learning disabilities were recruited. All had to be currently working clinically in this field, with previous experience of making decisions related to capacity. All participants volunteered to take part and agreed to give an hour of their time to be interviewed.

2.2.4 Participant details

Nineteen participants were interviewed. Five psychologists, five care managers, five community nurses and four psychiatrists. Further participant details are outlined in Table 1. (Information taken from the participant details questionnaire – see section 2.3.4).

Table 1. Participant details and experience of issues related to capacity to consent

PROFESSION	GENDER	AGE	NO. OF YEARS WORKING WITH PEOPLE WITH L.D.	FREQUENCY WITH WHICH DECISIONS RELATED TO CAPACITY TO CONSENT OCCUR IN PRACTICE	WHICH PROFESSIONALS MAKE DECISIONS REGARDING CAPACITY TO CONSENT?	TRAINING RECEIVED RELATED TO CAPACITY TO CONSENT
Psychologist	Female	32	8	6 Monthly plus	Multidisciplinary	2 x 1 day courses
Psychologist	Female	46	10	Monthly	Multidisciplinary includes SLT & OT	Own reading & service policy
Psychologist	Female	35	1.5	Yearly	Decisions made by carers	None
Psychologist	Male	50	23	Monthly	Multidisciplinary	None in last 5 yrs.
Psychologist	Female	49	3	Monthly	Multidisciplinary	None
Community Nurse	Female	37	10	6 Monthly	Psychiatrist	1x half day course
Community Nurse	Female	31	5	6 Monthly	Multidisciplinary	None other than on the job
Community Nurse	Female	35	17	Monthly	Psychologists & psychiatrists, aided by nurses	Own reading, none since own training
Community Nurse	Male	36	10	Weekly	Multidisciplinary	None since own training
Community Nurse	Male	31	10	Yearly	Multidisciplinary	None since own training
Psychiatrist	Female	50	10	Monthly to 6 monthly	Multidisciplinary includes SLT & OT	Trust and own training
Psychiatrist	Female	57	20+	6 Monthly	Multidisciplinary	None
Psychiatrist	Female	55	15	Weekly	Psychologists, psychiatrists	1x Trust course
Psychiatrist	Male	39	10	Weekly	Multidisciplinary includes SLT & OT	Professional experience & own training
Care Manager	Male	43	15	Weekly to monthly	Psychiatrists & psychologists	Adult protection training only
Care Manager	Male	46	26	Two monthly	Multidisciplinary	None
Care Manager	Male	46	15	Monthly to 6 monthly	Multidisciplinary includes SLT & OT	Not much if any
Care Manager	Female	43	20	Weekly	Multidisciplinary includes SLT & OT	Team discussion, none since own training
Care Manager	Female	32	10	Monthly	Multidisciplinary includes SLT & OT	None just service policy

SLT refers to speech and language therapy OT refers to occupational therapy

2.3 Measures and materials

2.3.1 Development of the methodology used

The study aimed to explore how professionals assess capacity to consent in practice and thus the methodology chosen needed to satisfy a number of requirements. For example, through the

method chosen, the criteria upon which capacity was assessed and the processes affecting professional decision-making needed to be made explicit.

After much discussion and thought, the initial design involved the use of case vignettes and two interview techniques; question asking (Hoffman, 1987) and verbal protocol analysis (Ericsson & Simon, 1993). Participants would be presented with a small amount of information about the case vignette and then requested to ask questions in order to gain more information about the case to assess the client's capacity to consent. It is argued that participants will ask the questions they believe to be relevant, providing a description of the order and the criteria on which a decision is made (Hoffman, 1987). During this process the participant would also be asked to think aloud, that is give a running commentary on their thoughts, thus providing information on their reasoning and thinking as they asked questions. Concurrent rather than retrospective verbal reporting is argued to eliminate the likelihood of differences in cognitive processing occurring at the time of actual task completion, when compared with later reporting on the task undertaken. The data provided by a verbal protocol is therefore a relatively pure and accurate representation of participants' thinking about the task, in that it is unaffected by further processing of the decision under consideration. This was the design originally piloted.

Piloting the methodology identified the strengths and weaknesses of its design. For example, the use of case vignettes and question asking appeared to provide a creative way of studying the criteria upon which decisions were based. Thinking aloud between asking questions seemed to place too much demand on participants who needed frequent reminding and thus it appeared to interrupt the flow of participants' thoughts, leaving the interview feeling somewhat disjointed. The difficulties experienced with thinking aloud may have been related to participants not having

enough experience of the area under consideration, a factor thought to make this process more difficult (Ericsson & Simon, 1993).

Through consultation with a number of researchers and discussion in supervision, the verbal protocol element of the design, that is thinking aloud during task completion, was dropped from the study's design. It was decided that once the participant had asked questions about the case the researcher would go over the interview and explore with the participant their reasoning behind the questions asked. Retrospective reporting on the task completed provides a less pure representation of a participant's thinking because it is reliant on memory and also the participant's thinking is open to further processing following the tasks completion. It was however in this case, seen as more appropriate in meeting the study's requirements. This design thus appeared to provide a framework for studying the assessment of capacity to consent in practice limiting the influence of theoretical ideas or the researcher's views on participants' decision-making. This version of the design was piloted. Piloting allowed the researcher the opportunity to standardise as far as possible the level of detail given in response to a question and in general the design appeared to work well.

The use of case vignettes and the question asking approach seemed to provide a framework for the task under consideration and thus an innovative and creative method for addressing how issues related to capacity to consent are thought about in practice.

2.3.2 Case Vignettes

Two detailed case vignettes were written for the research; one related to capacity to consent to treatment and the second related to capacity to consent to a sexual relationship. The process of developing the vignettes to be used in the study began by brainstorming in supervision the

clinical situations that might give rise to questions related to capacity to consent to treatment and capacity to consent to a sexual relationship. It was agreed that the scenarios chosen should be reasonably complex so as to present participants with a dilemma which would provoke considerable thought, but at the same time, scenarios representing those that clinicians are likely to have met in their own clinical work and therefore likely to have some previous experience of. Having determined the clinical situations upon which the vignettes would be based, the detail of each case was written in relation to the factors or information which the literature suggests is taken into account when assessing a client's competency. It was decided that if during the interview, a participant asked for information not already included in the vignette, the researcher would provide details in line with the case scenario. The vignettes designed for use in this research were not based on any specific cases with which the researcher had been involved, but were developed from the researcher's and supervisor's general experience of working with people with learning disabilities.

2.3.3 Participant details questionnaire

A short information sheet was designed to collect demographic details regarding professional status, gender, age, length of time working in learning disability services, amount of training received related to capacity to consent and experience of making decisions related to issues of consent (appendix 2.).

2.4 Ethical Considerations

Ethical approval was obtained from the Local Research Ethics Committees associated with each of the two Trusts (appendix 3.) and in the case of the social services department, where there was no ethics committee, approval was obtained from the Salomons Centre Ethics Committee

(appendix 4.). The research adhered to the British Psychological Society Ethical Principles and Guidelines (1998) and The Division of Clinical Psychology Professional Practice Guidelines (1995).

Participation in the research was voluntary, anonymous and based on informed consent. Two copies of the consent form were given to the participant, one of which they kept. The copy returned to the researcher was kept separately from the interview transcripts to ensure anonymity. The research did not require participants to talk about or refer to clients with whom they worked or had worked.

Each interview was taped. It was explained to participants that the tapes and transcripts of the tapes would be destroyed following full completion of the research. Confidentiality was maintained throughout the study. Following transcription of the tapes participants were identified by number and profession only. Following completion of the dissertation a copy was made available to participating services and a shorter report provided outlining issues, likely to be of interest to the service (appendix 5.).

2.5 Procedure

2.5.1 Introducing the study

The heads of each professional group in each service were contacted and initial information regarding the study was either sent to teams or presented to potential participants at team meetings by the researcher. An interview time was then agreed with those professionals who expressed an interest in participating. It was emphasised that participation in the study was voluntary and participants could drop out at any time without giving a reason for doing so.

2.5.2 Interviewing

Each interview began by introducing the research and the task to be undertaken. It was emphasised to participants that they were not being evaluated in any way. It was also emphasised that information given would remain anonymous and confidential. Participants were asked to read and sign the consent form (appendix 6.) and any questions were answered. Each interview was taped, and lasted between 40 to 90 minutes.

Having agreed to take part in the study, participants were initially given a short set of standardised instructions for completing the task (appendix 7.) with the opportunity to ask any questions. For each of the two vignettes the interview process was divided into two parts. In part one, the instructions given requested the participant to ask the interviewer questions to elicit more detail about the case vignette they had been given, in order to assess the client's capacity to consent. In part two, it was stated that the interviewer would go back over the participant's questions, exploring with them their thinking and reasoning behind the questions asked.

Having understood the task the participant was then presented with a small amount of written information about the first case vignette in which there was concern about the client's capacity to consent to treatment (appendix 8.). This read 'Bill has been complaining of a sore mouth, it is suspected that he will need some of his teeth removed due to infection. You have been asked to assess Bill's capacity to consent to dental treatment'. At this stage of the task the full details of the case vignette were known only to the researcher (appendix 9.). As the participant asked questions about the vignette, so the interviewer gave further information about the case. Once the participant had completed part one, reaching a point where they felt they had asked as many questions as they wanted, so the interviewer moved on to part two. The same process was then completed for the second vignette, where the participant was given basic initial information about

a case in which there was concern about the client's capacity to consent to a sexual relationship (appendix 10. & 11.). The initial information read, 'Wendy has been in a relationship with Mark for about a year. Mark is saying that he would like their relationship to become sexual and has been asking to stay in Wendy's room. You have been asked to assess Wendy's capacity to consent to a sexual relationship'. At the end of the interview, each participant was asked to complete the participant details questionnaire (appendix 2.).

2.6 Data Analysis

2.6.1 Interpretative phenomenological analysis

Tapes were transcribed and the data analysed using IPA. IPA aims to explore in detail participants' views of the topic being studied, in this research the criteria and the processes affecting the assessment of capacity to consent in people with learning disabilities. The process involved in completing IPA described by Smith et al. (1999) was used to guide the analysis of the data.

The researcher initially read and re-read the transcripts immersing herself in the data. At this stage, it was decided that the approach to assessing capacity to consent to treatment (vignette one) and to a sexual relationship (vignette two) were sufficiently different as to warrant separate analysis. Thus, the process of analysis described below was completed for both case vignettes.

Smith et al. (1999) suggest that when a large number of participants have been interviewed it is not initially cost-efficient to complete an extensive analysis of all transcripts. Thus initially the interviewer read one transcript from each profession noting down in the left-hand margin any initial thoughts or possible codes. Then on rereading, any possible themes or codes were noted

down in the right hand margin (an example section of transcript including notes is provided in appendix 12.). The themes at this stage were kept broad as suggested by Smith et al. (1999) and referred to large amounts of texts, shorter paragraphs or individual sentences. A list of the themes to emerge from the analysis of these initial four transcripts was then made, from which groups of themes were identified (appendix 13). Throughout, the researcher kept notes concerning ideas and the connections beginning to emerge between themes.

The remaining transcripts were then read and coded, with the researcher remaining alert to new themes. Smith et al (1999) emphasise the need during this stage to look at each transcript afresh so that the emergence of codes comes from the text. However, they also recognise that the sequential nature of processing will inevitably orientate analysis towards certain aspects of the data given the themes already identified. Having completed the coding for all transcripts the interviewer began to analyse the groups of themes, for higher order themes shared across all participants, keeping in mind the need to develop an understanding of participants' experiences.

Having identified the broad themes shared across participants these were then more intensively explored. This stage involved re-examining transcripts 'through a more focused lens' (Smith et al. 1999). Whilst many of the verbatim extracts from the transcripts related to these broad themes had already been identified through the initial coding process, the researcher went back over the transcripts to make certain all sections of text related to each theme were identified. This was completed on the computer through a process of copying and pasting between files, so that all extracts were grouped according to themes. This also involved considerable cross categorisation given that sections of text could be related to more than one theme. Thus through this process the subcategories relating to each broader or overriding theme began to emerge more clearly. Having completed this the researcher then reread the analysis looking for themes or categories that could

be merged, each time looking to create a greater understanding of the data and the connections and tensions between themes and categories. Having completed the analysis, the researcher reread a number of transcripts to check that the themes and categories that had emerged reflected the original data. This process resulted in the final themes and categories presented in section 3.

2.6.2 Reliability and validity

The extent to which qualitative research can achieve a high standard of scientific rigour is a complex area (Lincoln & Guba, 1989). The difficulties appear to relate to the idea that the same standards need to apply to both quantitative and qualitative research. However, these research traditions are underpinned by quite different ideas i.e. qualitative methods place emphasis on meaning and subjective experience, whilst quantitative methods are more concerned with objectivity and quantification. There is thus an ongoing debate with regard to whether the same criteria can or should be applied to both these research traditions (Mays & Pope, 2000).

However, the intent of all research is to produce credible findings and therefore all research must undergo critical appraisal (Hinds, Scandrett-Hibden & McAulay, 1990). The criteria used to evaluate qualitative research must be closely related to the questions being asked (Elliott et al. 1999), as well as taking into account the distinctive goals of qualitative research (Mays & Pope, 2000). The measures used in this study are detailed below.

a) Auditability

Charmaz (1995) argues that the interaction between the researcher and the researched produces the data upon which the studies conclusions are based. Therefore, this interactive process needs to be made explicit in order for it to be scrutinised by others and conclusions regarding its validity drawn (Stiles, 1993; Mays & Pope, 2000). To provide a reflexive account of the research

process in this study, a diary was kept throughout the period of the research and documents the decisions made about the research process and the researcher's thoughts and ideas about the process and the analysis (appendix 14.). The research was also regularly discussed in both individual and peer supervision enabling any potential biases the researcher might hold to be explored. The process of IPA is also made explicit above.

b) Respondent validity

Respondent validity refers to the extent to which the findings are representative of participants' views regarding the subject under study and is important in judging the quality of the researcher's interpretations (Silverman, 1993; Mays & Pope, 2000). In this study, the analysis of the results was fed back to participants in writing. Participants were asked for their comments both on the method used by the researcher for exploring capacity to consent and the research findings (appendix 15.). Participants' comments are discussed in section 3.6.

d) Inter-rater reliability

Inter-rater reliability serves to ensure reliability of the analytic process measuring consistency and repeatability of the research (Coyle, Good & Wright, 1994; Pope, Zieland & Mays, 2000). In this study, an independent rater was asked to assign all extracts taken from four randomly selected transcripts to the themes and categories identified by the researcher. Cohen's Kappa coefficient of agreement (Siegel & Castellan, 1988) was calculated based on establishing agreement between the two raters, the results of which are presented in section 3.7.

e) Rhetorical power/ generativity

The quality of the research should be judged by the extent to which the results are effective in persuading those working in the field to accept them (Henwood & Pidgeon, 1995; Elloitt et al.

1999). To allow the reader to judge the research in this respect examples from the analysis are presented with the results and its clinical implications explored in the discussion.

3. RESULTS

3.1 Summary of results

Analysis of the transcripts was based on the initial research questions presented in section 1. 7. A summary of the themes and categories to emerge from the analysis are presented in Table 2. This is followed by a detailed presentation of the themes and categories with examples of verbatim extracts taken from the transcripts.

Table 2. Capacity to consent summary of themes and categories

3.2	Vignette 1. Capacity to consent to treatment	
3.2.1	Learning disability	a) Global level of functioning b) General level of functioning c) Specific assessment of skills relevant to the situation
3.2.2	Seriousness of the situation	a) Problem severity b) Risks or consequences of not treating c) Effect on quality of life/mental state d) Possible complications
3.2.3	Understanding client's decision	a) Negative past experience b) Impaired capacity/less able than assume c) Lack of decision making experience d) Not informed, incorrect information given e) Decision influenced by others
3.3	Vignette 2. Capacity to consent to a sexual relationship	
3.3.1	Learning disability	a) Global assessment of functioning b) General assessment of skills and abilities c) Specific assessment of sexual knowledge
3.3.2	Understanding the current situation	a) Determining client's choice b) Development of the client's relationship c) Dynamics of the relationship/client characteristics d) Influence of others
3.4	Factors affecting the assessment of capacity to consent	
3.4.1	Assessment of capacity vs Intervention/Treatment	
3.4.2	Rights of choose vs Right to protection from harm	
3.5	Differences between professional groups	
3.5.1	Professional role	

3.2 In practice, how do professionals assess capacity to consent to treatment in people with learning disabilities?

Three main themes emerged from the analysis of the transcripts related to the assessment of capacity to consent to treatment; ‘assessment of learning disability’, ‘seriousness of the situation’ and ‘understanding the client’s choice’.

3.2.1 Assessment of Learning disability

Participants requested information about the client’s learning disability at three levels, that is information regarding their ‘global level of functioning’, ‘general skills and abilities’ and ‘specific skills relevant to the situation’. Participants appeared to move along a continuum from gaining a broad understanding of learning disability, to gaining a more specific understanding with regards to the treatment being considered. However, not all participants explored the client’s level of learning disability to the same degree. This appeared to be related to professional role and is discussed further in section 3.5.

3.2.1.1 Global level of functioning

Most participants requested information about the client’s global level of functioning asking for example, the client’s level of learning disability, where the client lived and what level of staff support the client received. These questions were described as assessing the likelihood of the client being able to consent, an ‘exclusion type of question’ (Psychiatrist 16.).

‘Level of learning disability gives you a rough idea of where the patient is at and moderate learning disability is more likely to tell you what you want to hear, severely

learning disabled won't understand you or at least they might understand but get to the stage where you are going to pull their teeth out and they will run a mile and the mildly learning disabled, well you'd think you were on a good wicket with them.' (Psychiatrist 1.)

'Well, it's just that if you lived in a semi-independent place then that proves he is very capable. The more staff support often means the less able you are to make choices and decisions for yourself.' (Nurse 13.)

However, the limited nature of this information was acknowledged explicitly by some participants and implicitly by others in that they later requested more in-depth information about the client's level of learning disability.

'You can assign a label and that but it is often more useful to find out what they can and can't do for themselves and see if he is exercising choice and consent in other areas...' (Psychologist 3.)

3.2.1.2 General level of functioning

Assessing the client's general level of functioning concerned obtaining information about the client's actual functioning in other areas of their life. In general, this was about the skills or abilities perceived as needed in making a decision related to the treatment under consideration and therefore seen as an indication of the client's ability to consent to that treatment. For example, participants requested information regarding the client's level of independence, skills, ability to communicate, make choices, decisions and consent.

'Can he choose what he is going to do? How is his self help skills? Can he budget? Can he travel on his own? Would he know what to do if he got lost? Can he use the telephone?' (Psychologist 9.)

'I was interested in those (decisions he makes around the house)¹ because they are indicators of him being able to make choices and being able to give consent, so the next thing I wanted to know is to what extent is he consenting to things now...' (Care Manager 2.)

3.2.1.3 Specific assessment of skills relevant to the situation

Questions posed by participants reflected the functional abilities perceived as needed by the client to have the capacity to consent to the treatment under consideration. This included questions about the client's knowledge of and understanding of the procedure, understanding of the consequences, reasoning skills and ability to communicate their decision. The aim of such questions appeared to be to understand both how able and how informed the client was. The degree to which the client was informed also related to understanding the client's choice and is explored further in section 3.2.3. The information gathered regarding the client's specific skills was used by participants to look at the client's capacity to consent and/or how to support the client with their current situation.

'Communication skills, his ability to connect his symptoms with his teeth problem or tooth problem, his ability to recall his previous experiences and his rationale for not wanting to proceed further because it is painful would imply to me that he has the capacity to be functioning and therefore I think he has the cognitive skills to be able to

¹ Words in brackets are those of the author

process a lot of information, because I mean we are talking about the past, present and future.’ (Psychiatrist 16.)

However, from the analysis there did not appear to be any consensus on the level of understanding needed nor how this should be assessed with a small number of participants explicitly acknowledging this difficulty.

‘It’s more about understanding how much he is getting in, because you know, you can easily misjudge these things, I mean you talk to somebody, and they give the answers that you wanted but do they really understand what they are talking about. Or do we as professionals understand how we need to communicate to them.’ (Nurse 8.)

3.2.2 Assessing the seriousness of the situation

Assessment of the seriousness of the situation appeared to be a consideration of the client’s decision not to have the treatment and the risks that that may pose. Where the current situation was assessed as serious or the risks to the client seen as unacceptable, then the client’s decision not to undertake the treatment was seen by most as not in their best interests. The situation was then less likely to be considered in terms of the client’s capacity to consent and more likely to be considered in terms of intervening to support the client in having the treatment.

‘To determine the risks of looking at doing nothing against the benefits of getting him to the dentist really.’ (Care Manager 15.)

However, there did not appear to be agreement amongst participants on either the factors contributing to the assessment of seriousness nor on what level of risk was considered too high.

3.2.2.1 Problem severity

Assessment of the problem severity was reflected in participants' questions about the life threatening nature of the situation and medical opinion as to the urgency or need for treatment.

'I'd need to speak to the dentist to see how severe the situation is.' (Nurse 8.)

'(Dentist's view of problem) That's about getting an expert opinion, saying yes there is a problem' (Care Manager 17.)

3.2.2.2 Risks or consequences of not treating

Thinking about the risks of the current situation and or the risks of not treating was apparent in participants' questions about the risks of the current intervention to alleviate the problem and the longer term consequences to the patient of leaving the problem untreated.

'I would kind of look for a medical opinion actually and say well, OK, here's a chap who says I want to be on whatever the painkiller is, for a year, does that matter or doesn't it.' (Care Manager 14.)

'OK what are the consequences of him not going to the dentist from a medical point of view, what is the major risk?' (Psychologist 11.)

3.2.2.3 Effect on quality of life/mental state

Participants' questions concerning the current impact or effect of the client's pain were reflected in questions about how it was affecting relationships with others, restricting activities, affecting his mood, mental state and general ability to function.

'If it is affecting other facets of his life, in other words, it is preventing him from going to the day centre, his behaviour is changing etc really, it is more serious than just a sore mouth.' (Care Manager 15.)

3.2.2.4 Possible Complications

This was assessed through questions considering the possibility of complications arising from the cause of the client's learning disability, other physical health problems or as assessed by medical professionals.

'(Is Bill epileptic?) Just a basic nursing question that we need to know if you are going to do anything medical with anybody.' (Nurse 13.)

3.2.3 Understanding client's decision

All participants looked for an understanding of the client's decision not to undertake treatment. In most instances, the need to understand was linked to finding a reasonable rationale for the client's choice.

'Again really, are there specific, are there good reasons for this person to be anxious about going to the dentist.' (Psychologist 4.)

Participants' understanding of the client's choice were categorised into two groups. 1) those reasons which were internal to the client i.e. 'negative past experience', 'impaired capacity/less able than assume' and 'lack of decision-making experience', and 2) those reasons external to the client i.e. 'not informed, incorrect information given about treatment' and 'decision influenced by others'. The client's choice was predominantly understood in terms of a 'negative past experience

and/ or 'not informed, incorrect information given about treatment'. The majority of participants went on to consider a means of intervening to assist the client in changing their decision and under-going treatment.

3.2.3.1 Negative past experience

A large number of participants understood the client's choice in terms of a negative past experience which the client did not want to repeat.

'I think I would want to explore with Bill what it was that was such a painful experience, and I would hope, I would ask him to explain to me in his own language as easily as possible what it was that was such a bad experience in the past.' (Nurse 6.)

The client's response was either perceived as a normal and thus understandable response or more commonly, a response that was pathological suggesting the client, needed treatment. With regards to the latter, participants went on to discuss ways in which they might intervene to alleviate this problem.

'A lot of adults without learning disabilities make exactly the same decision.'
(Psychologist 3.)

'...get more assessments and work more on a sort of phobia level and get him used to the idea, we did it with someone here.' (Psychiatrist 18.)

3.2.3.2 Impaired capacity/less able than assume

The possibility of the client's capacity being in some way impaired was explored by participants' through questions about for example, the client's physical or mental ill health. The possibility that the client might be being assumed to be more competent than he was, was explored by participants' through questions about the client's age and communication.

'I wanted to get a picture of what he was like. Was he sort of reasonably well functioning person, whether with his obvious difficulties or was he completely psychotic or was he autistic or what.' (Psychiatrist 12.)

'(Does the client have physical health problems?) I just wanted to know if there was anything else affecting him... the problem or his ability to consent.' (Nurse 7.)

3.2.3.3 Lack of decision-making experience

The client's decision-making experience or possible lack of it was acknowledged by a small number of participants.

'I was trying to gauge how much choice he had in other areas of his life, which is something I would maybe follow up on some more. I mean how used is he to making these sorts of decisions and how used is he to having his views listened to.' (Psychologist 10.)

3.2.3.4 Not informed, incorrect information given about treatment

The client's decision was understood in terms of the information they had received about the treatment. That is the client was either perceived as uninformed because they had not been given

enough information or had been given incorrect information, or the client had not been presented with information in a way in which they would be able to understand.

‘The main thing for me was whether he knows, he's been told what the procedure involves if he has an operation... and whether he understand all the procedure and how the information is put across to him I think is very important’ (Psychologist 9.)

Where the client was perceived as uninformed he was by some also seen as being likely to have agreed to the treatment if he had been correctly informed.

‘Again if he isn’t (aware of the consequences) then I don’t think he’s making, he’s not in a position to make an informed decision, even though he has, it sounds to me although he has got capacity to make these decisions, but he doesn’t sound informed.’ (Psychiatrist 16.)

3.2.3.5. Decision influenced by others

Some participants questioned the opportunity of the client to make their decision free from the influence or views of others.

‘I was wanting to get a sense of how stressed the staff are about it, how adamant they are that he must go and he must go now or whether their motivation is not to do that at all, because he is refusing to accept that and to just give him the painkillers when he asks for them.’ (Psychologist 10.)

3.3 In practice, how do professionals assess capacity to consent to a sexual relationship in people with learning disabilities?

Two main themes emerged from the analysis of the transcripts related to the assessment of capacity to consent to a sexual relationship; ‘learning disability’ and ‘understanding of the current situation’.

3.3.1 Assessment of the client’s level of functioning

Similar to the assessment of capacity to consent to treatment, participants asked questions regarding the client’s global level of functioning, general skills and abilities and specific skills relevant to the situation, as if systematically seeking more depth. However, in contrast to the assessment of capacity to consent to treatment, participants appeared to place most emphasis on the specific assessment of the information, skills and abilities perceived as needed in making a competent informed decision with regard to entering a sexual relationship. The information gathered through assessment of the client’s learning disability appeared to relate to both assessing capacity and to ways of working with or supporting the client.

3.3.1.1 Global assessment of functioning

The majority of participants requested information regarding the client’s global level of functioning, ascertained by asking about for example, their level of learning disability, where they lived or type of day-centre attended. The majority of participants requested information about both clients’ levels of learning disability. Again, as in the first vignette these questions appeared to be assessing the likelihood of the client being able to consent.

'Yeah again, you know, that's (level of learning disability) quite important. Some of them they are quite able to understand what's going on, and some of them, you know, it's quite difficult to assess at what level they are functioning at you know, Whether they can consent or not.' (Nurse 8.)

3.3.1.2 General assessment of skills and abilities

Approximately half of participants explored questions about the client's general skills and abilities. However, few assessed this in-depth. Where questions were asked they appeared to be a means of broadening information following questions about the client's global level of functioning, or elaborating on information that had been given about the client's skills or abilities with regards to the specific situation:

'And in terms of daily living skills have they had assessments? What their particular skills or strengths are?' (Psychologist 10.)

'Does she make choices on a day to day basis about other things?' (Nurse 13.)

3.3.1.3 Specific assessment of sexual knowledge

The client's skills and abilities were predominantly explored through questions directly related to the specific situation by all participants. The aim of such questions appeared to be tied to assessing both how able the client was and how informed the client was. This information then appeared to be used to look at both clients' capacities to consent and the current risks in the relationship. Assessment of these two factors were often not independent of each other.

'They are slightly different, but I think both are valid, because to give consent it needs to be informed and it goes back to this capacity, um and I think she certainly has to have a basic understanding through psychosexual education of what it entails and I think we would have to be confident that she has the basic understanding of what it entailed. So that's really about the information that she is given and learnt and retained etc. etc. Once she had that then I think she would have capacity because they're all interlinked.' (Psychiatrist 16.)

However, with specific regard to the assessment of how informed the client was, participants frequently requested information on the client's previous experience of sexual relationships, sex education, sexual awareness and age. This was also often related to thinking about what support or education was needed and how it might need to be offered so that the client could make an informed choice or the risk of for example, pregnancy be reduced.

'I think it is important for people to be fully informed about these things, how can she make a decision if she doesn't know what it is all about.' (Nurse 7.)

'Well, you would have to think about contraception and also very strongly advise and that would be part of the sex education package. Um. Presumably sexual help, sexual disease, that would have to be thought about. But he's not a man who's had lots of sexual relationships, but clearly you wouldn't want her to get pregnant. And the sort of circumstances can be quite difficult in a residential home, but sometimes couples can sort of move in on their own can't they.' (Psychiatrist 12.)

With regard to the assessment of how able the client was, participants asked both broad questions related to the client's general understanding, as well as more specific questions. The more specific questions related to, for example, the process of sexual intercourse, the possible consequences and risks of intercourse, and the ability to remember and retain information. A few participants explored the client's understanding of both the emotional and physical side of a sexual relationship.

'So I have been asked to assess Wendy's capacity to consent, again one would want to be sitting down with Wendy first of all, for quite a while and gaining some knowledge of her level of understanding and I suppose, I'm not as clear as that, her level of understanding of sexual intercourse and what it means and what the implications are and what the consequences are and everything, so, much more about that.' (Psychiatrist 18.)

'I might in my assessment I would (use) pictorial materials about how much, what she knows about it and what's she understanding and what's the meaning of that relationship with Mark..... whether she is in love with him, whether she understands what love means. What are her feelings towards this relationship, about this man.' (Psychologist 9.)

There did not appear to be any agreement on the skills or abilities needed by the client to be assessed as competent in this area.

'The fact that there is somebody talking to her about pregnancy and contraception made me go urrh, because I just think that's making such a horrendous deal and making it terribly complicated.' (Nurse 13.)

However, Nurses seemed to be clearer about the technique or assessment tools they might use, others commented on this being a difficulty.

'The first thing I'm going to do with Wendy is in this instance, is to probably carry out a sexual knowledge assessment so to go through her understanding of the background, relationships, of bodies, public and private and other things... safe sex.' (Nurse 5.)

'I think it is just going to come down to trying to assess her understanding of what is involved and what the risks are, to see if she can actually weight up those issues, our biggest problem is how to weight up the pros and cons about something so she in making her own choice there is always pressure from somewhere else.' (Psychologist 4.)

Although the emphasis was on the assessment of the referred client's ability, most participants also considered the client's partner's understanding. In these cases, the partner's abilities appeared to be considered in terms of thinking about the support or education the couple might need and reducing the risk of pregnancy etc by making sure the client's partner was also informed. A small number were unsure of how relevant assessing the partner's learning disability was in the context of the decision under question.

'I think yeah, too much emphasis being placed on Wendy and that we needed to make sure that although Wendy can practice safe sex if Mark didn't know how to or didn't appreciate what safe sex was, then maybe she could be slightly more vulnerable.'

(Nurse 5.)

3.2.2 Understanding the current situation

Questions reflected the need to gain a picture of the current situation and therefore the role of the professional, the client's choice and the factors that might be affecting the client's choice.

3.3.2.1 Determining client's choice

Questions regarding the client's choice appeared to have several functions in assessing capacity to consent. These were to establish the current context, to begin to develop hypothesis about her choice and to consider the role of the professional in this situation.

'That would create a very difficult situation because certainly I can't see there is any justification for us trying to persuade Wendy. I think that would be inappropriate and Wendy has got to feel confident that this is what she wants, again perhaps if she is ambivalent umm, perhaps they ought to be encouraged to wait for six months to see how they feel.' (Care Manger 19.)

'Well I think it is very important, because that gives you an indication that she, either that she doesn't understand the implications of sex, either she could have mixed feelings towards Mark and is she frightened because she doesn't know or she is under pressure, Mark's pressure'. (Psychologist 9.).

3.3.2.2 Development of the client's relationship

The client's relationship with her partner was explored in terms of its appropriateness. This included an exploration of how it developed, its present functioning and in a small minority of cases its future. Such questions again also reflected the need to assess the current risk of pregnancy.

'They are living together; are they or has it simply occurred because she is there and available to become a sexual object for him or does he genuinely like her?' (Psychiatrist 1.)

'Whether she saw it as very much a kind of, I suppose a very kind of secure boyfriend girlfriend relationship, you know, or they might just hold hands or they might call each other boyfriend and girlfriend but they actually spent no time together whatsoever. Or was it somewhere... a relationship where, there was actually quite a high physical interest, maybe with heavy petting going on in the past, you know, those sorts of things, um. Yeah how far had they actually gone down that route.' (Care Manager 17.)

3.3.2.3. Dynamics of the relationship/client characteristics

Questions also focused on the dynamics of the client's current relationship predominantly considering the potential for abuse, coercion or pressure. The power differences or potential for coercion was also explored through questions relating to both partners' personality characteristics.

'It's difficult because it gets moral then. Subjectively I would be concerned to feel that she had some idea that a sexual relationship goes with an emotional feeling which

is very subjective and may be my own, my own moral position. I'd be unhappy if she was saying that she didn't care about him at all and she had no feelings for him but it was alright to do this because he wanted to or something like that. So the idea that she can see things that she wants from it and potentially if she wanted it for the sex and that was her way of seeing it, that might be another reason as well, but it is about having reasons that show there is a benefit for her that she can perceive, rather than just other people getting her to do things. And a sense of whether she feel exploited is difficult, but whether she feels it was something she wanted to do or whether it was something other people wanted her to do.' (Psychologist 4.)

'I think one's attitude to a chap who is potentially violent and aggressive would be very different than someone who is sort of, of a more sort of thoughtful kindly disposition, you know, is he interested in her.' (Psychiatrist 12.)

Thus, in making a decision about the client's capacity to consent participants appeared to want to know that the client was making a decision free from coercion, in a relationship which would not be considered abusive.

'That's with my sort of risk assessment hat on. I mean that seems to be the obvious opportunity (time alone) where if we have concern for that abusive element that's where it is going to take place. But it also tells us, and I think it's very important this information that he respected her wishes. Which is very important and strengthens our belief that there is a two-way give and take relationship.' (Psychiatrist 16.)

3.3.2.4 Influence of others

The majority of participants considered the influence of others on the client's decision. This included the possible influence of parents, staff and other client's. Whilst exploration focused predominantly on understanding the client's ambivalent feelings, some participants also explored the influence of others on her partner's choice.

'Also what messages does she pick up from elsewhere and if she's expressing doubts, are they the doubts of others. Because she has been told that she should doubt this and it's not right or is it something that she genuinely feels, and is happy or unhappy with and it just made me think she is getting an awful lot of mixed messages at the moment.' (Care Manager 17.)

'Because he may be simply responding to peer pressure or he may be just saying he wants the relationship to become sexual because other people have told them that they are having sex with their girlfriend. He may not actually want it himself. But he feels he has to do it, or he thinks that's what one does with one's girlfriend, and he may not realise that it is possible to have a platonic relationship as well.' (Nurse 6.)

The influence of parents and staff in the majority of cases was considered paternalistic and protective. Participants were clear that neither staff nor parents had the right to make such decisions for or influence the client and therefore talked about interventions to alleviate this pressure on the client.

'If I knew that the parents were anti a relationship which might actually be an appropriate relationship, a good relationship to move forward, then someone will need to

do some work with the parents, as Wendy is going to continue getting mixed messages if we are saying yes, OK off you go and she is getting from the parents different, so it would make me think we need to try to get them on board somehow and so talking to them would be really important because that could jeopardise everything. Same with the staff.' (Psychologist 10.)

3.4 What factors affect the decision-making process, when assessing capacity to consent in people with learning disabilities?

Implicit in the assessment of capacity to consent across both vignettes were two overriding factors; 'assessment of capacity versus intervention/treatment' and 'rights of the individual versus protection from harm'. From the analysis, the balance between assessing capacity and intervening to protect the client or alleviate the situation, appeared to be heavily influenced by participant views on the right of the client to make their own decisions and their right to protection from harm.

3.4.1 Assessment of capacity versus Intervention/treatment

The majority of participants in their approach to the vignettes sought both to assess the capacity of the client and the possibility of intervening or treating to alleviate the situation or protect the client from harm. However, the balance between the assessment of capacity and intervening to alleviate the situation was viewed in different ways by different participants. For example, many participants were clear that if in practice they were presented with the first vignette, they would want to assess for treatment before considering the situation one in which the client's capacity needed to be ascertained.

‘Could (the client) be helped with in terms of treatment or you know, helping them overcome a fear or phobia that’s got a particular cause, umm, so I suppose what I want to say is that you wouldn’t necessarily want to get pushed into this being the thing to do determine consent, unless it was a really urgent physical problem that needed treatment and people were really worried in the immediate term I wouldn’t really want to worry about assessing someone’s capacity to consent unless it was that. There are other things that you could be doing which are more like a treatment approach.’ (Psychologist 4.)

‘The capacity to consent is the absolute last resort, it really is, particularly from our experience in this team, you know, it is something that wouldn’t be invoked, unless you know, there was no other way...’ (Care Manager 15.)

Whilst in vignette two this was less explicit, participants were, in the majority of cases, clear that they would want to support the client in their relationship through for example, providing education or support/protection, rather than purely assessing capacity.

‘If an assessment of this nature landed on our desk, again, it would be more about Wendy’s sexuality and her physical, you know, social, and physical and psychological well being and promoting good health for all, as opposed to ascertaining her ability to consent.’ (Nurse 6.)

All participants were clear that support would be offered to the client in some form. However, in the case of vignette one the degree to which the client was expected to comply with the support

offered differed greatly amongst professionals. For some, the assessment of capacity was central to their decision with regard to the extent in which they should intervene and/or expect the client to comply.

‘There’s quite a lot of things you have to work through there (assessing to establish possible ways of working with client). You know, but at the end of the day, none of us has got the right to sort of you know, to make Bill do what he doesn’t want to do.’ (Nurse 8.)

‘But I will still argue from the information I have, um, OK, so obviously he is limited to a certain extent, it sounds as if he could make an informed decision and we would have to respect that. Although it would not stop us continuing to try and persuade him that it’s in his best interests to go for it.’ (Psychiatrist 16.)

For other participants the client’s compliance with treatment was the central aim and the assessment of capacity secondary.

‘So along the way, each step (whether) looking at pictures and helping him gradually think about going to the dentist or whether umm, it was getting everybody in a team together and assessing the risk, it would be about finding a way that he would have the treatment done... I could in most instances see us trying to persuade the client to have the treatment anyway.’ (Care Manager 19.)

In the case of vignette two where the client was seen to be making a safe choice, compliance was less of an issue. However, intervening in terms of providing information and/or slowing down the

course of their relationship in order to protect the client from distress was still viewed as essential by most.

‘My initial feelings are, and this is really ball park initial feelings because we couldn’t make a decision, is that they probably are both able to consent but they both need some support and some education and I feel quite happy at the moment because she is making the safe decision, at the moment and what I would be wanting to do is again get to know them both but preferably her, probably refer to a male community nurse to get to know Mark and I would be saying to her, well, not being sure is fine and the equivalent to when in doubt do nothing and let’s talk about this and let me help you understand what it entails a bit and um, what you’ve got is something really special and it’s OK to take your time.’ (Nurse 13.)

3.4.2 Right to choose versus Right to protection from harm

Decisions made by participants in relation to the assessment of capacity and or the decision to intervene appeared to be linked to participants’ views regarding the right of the client to choose and therefore respect for their choice versus the right to protection from harm and therefore professional responsibility to intervene. For the majority of participants, the right of the client to be protected from harm appeared to outweigh the right of the client to choose.

‘If however, it is affecting other facets of his life, in other words, it is preventing him from going to the day centre, his behaviour is changing etc. really, it is more serious than just a sore mouth. But in fact is impacting on his quality of life, then the duty of care that we have to ensure that he gets treatment becomes equally as important as his

choices really. Ultimately he has a learning difficulty and there is a duty of care that the residential service must be seen to be upholding.' (Care Manager 15.)

Reducing the risk to the client in both vignettes was seen as in the client's best interests and therefore within the professional's duty of care to that client. The client's capacity to make decisions for themselves was in most instances secondary to the client's best interests.

'Well... this is quite an easy one really because you're looking at someone who is suffering and needs treatment um, who's got a moderate learning disability and may or may not consent and I think there is a case to be made for it going ahead under common-law because its in the best interests of the patient... decayed teeth are very bad for people's health they can cause all sorts of things.' (Psychiatrist 1.)

'For me again, I come back to this thing about how do we kind of manage the issues of, ...contraception and then one might agree yes, or no at that point to the move, so for me it's actually, it seems quite symbolic, that feels like, that feels quite symbolic saying yes she can stop over night or not or yes you can, so I would start to interfere, where did that power come from, where do those assumptions come from, but for me that feels like quite a, I would want more evidence that this is what Wendy wants before I gave permission to that, not because I don't think essentially why shouldn't they?... but I would want an awful lot of convincing at this point that if we as a staff group, knew enough about Wendy to say yes.' (Care Manager 15.)

Thus, where the client was assessed as being at serious risk the assessment of capacity was no longer seen as important. Whereas if the risk to the client was considered low then the assessment

of capacity was given more weight. (Assessment of risk was also linked to participants' view of how safe or acceptable the client's choice was).

'I would think it would have to be respected. It's a serious complaint and it's obviously causing him a lot of pain and maybe affect his ability to eat and digest food and stuff like that, it's not life threatening.' (Nurse 6.)

'We're comfortable that it's not an abusive relationship, or certainly I am from what you've told me, then I would say that she has every right, once we'd looked at the taking into account the contraceptive profile, and that was all sorted out, we have no qualms about that, yes, I would say she would be in a position to give a consent and go ahead.' (Psychiatrist 16.)

Some participants recognised the subjective nature of the decision they were making, whilst others appeared less aware of the effects of making a decision which went against the client's choice.

'I think the whole issue is riddled with problems, there is no specific guidance or agreed method of assessing this kind of issue you have to do it in terms of the specific individual ability to understand that problem and I do feel you are left with a kind of, no matter how objective you are trying to be you are left with some kind of subjective issues coming along about whether you think the person should have it done or not, umm, which shouldn't be the issue but it is hard to avoid that getting into it.' (Psychologist 4.)

'But on the whole, I don't see why she shouldn't be allowed, that's terrible isn't it, - allowed – allowing somebody to have a sexual relationship because yeah, she knows about the safety side of things and maybe look at her assertiveness anyway.' (Nurse 5.)

The balance between respecting the client's choice and the professional role's to act in the client's best interests was most explicit in the way in which participant's viewed the final decision as being made. Many participants' viewed this as being made by a multidisciplinary team. The emphasis here appearing to be on determining the client's best interests and hence how to intervene rather than on purely assessing competence.

'If he wasn't amenable then what we would do on this team is hold a multidisciplinary meeting and we'd ask the dentist to participate and a member of staff from the care home and if Bill has an advocate or any relatives and we would probably have one of the senior staff from the team and possibly the team leader for the social workers. So we would get the full range for the different professions to discuss what would be the risks if Bill doesn't have this treatment if we accept his ability to say no what are the risks and we would complete a risk assessment. If our risk assessment then concluded that the risk of not having the treatment was far to great then we would have to ask the dentist to complete the treatment under duty of care and we might need to look at strategies for how we actually get Bill to the dentist's surgery, so we again need to look at medication for a very brief period just for the treatment and the pain killers.' (Care Manager 19.)

3.5 Are decisions made relating to capacity to consent, made differently by different professional groups?

Virtually all participants were keen to emphasise that the views of a number of different professionals should feed into the assessment of capacity to consent, different professions seen as having different skills or roles.

'I would press people to call a meeting with speech and language therapist in particular, the community nurse and invite the GP as well. That would be my core people.' (Psychologist 9.)

3.5.2 Professional role

The differences in the way professional groups approached the task appeared to be minimal. Where there were differences they appeared to lie not in what participants' viewed as needed to be assessed, but in their view of their own and others' roles.

The assessment of the client's skills and abilities was viewed as the role of either psychologists or speech and language therapists. Other professionals talked about being unable to fulfil this role. (The view of the role of speech and language therapy (SLT) appeared to be affected by service differences in that SLT was more prominent in one service than the other. Participants working in the service where SLT was more prominent were more likely to refer to its role in the assessment of specific skills and abilities related to understanding the decision being taken).

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'Well I would obviously want a psychological opinion on that and ah, speech and language therapy to be much clearer about her, yeah her abilities to be coerced into something she doesn't want to and I suppose you are getting into all the realms of abuse and everything else at that stage so you have got to be, yeah. I mean that is an issue so they are not equally consenting adults it is an unequal relationship.'
(Psychiatrist 18.)

Direct work with the client in both assessing and intervening was seen as being predominantly undertaken by community nurses.

'I might go along and see him or I might, it probably would be a referral to the community team and so we might suggest that one of the community nurses went along to see him, to see if they could strike up a relationship.' (Psychiatrist 12.)

'Well she might have had a community nurse do sex education with her.' (Nurse 13.)

Where medical opinion was sought participants talked about seeking the views of the GP, dentist or psychiatrist.

'You know, because then you have actually got a medical opinion that says this is actually unsafe, whereas the tooth thing at the moment doesn't appear to be unsafe.'
(Care Manager 17.)

3.6 *Respondent validity*

Two respondents replied and provided comments on the study's design and findings. Comments regarding the methodology used were positive. Comments with regards to findings were also predominantly positive.

'I think that your study accurately reflects how various professionals determine capacity to consent, without necessarily dealing with the practicality of how this is actually done. Having said that I am not clear whether you set out to cover the latter point.' (Psychiatrist)

Both respondents commented that the study correctly found this decision to be multifaceted and complex. One respondent felt therefore that this made it essential that decisions related to capacity needed to be taken by a multidisciplinary team.

3.7 *Inter-rater reliability*

Cohen's Kappa co-efficient of agreement was calculated separately for vignettes one and two.

Vignette 1. = 0.82

Vignette 2. = 0.78

4. DISCUSSION

4.1 Outline of the discussion

The research findings and their theoretical implications are initially discussed. Following this a tentative model is suggested concerning how capacity to consent is assessed by professionals. The study's design is then critically reviewed and the clinical and service implications explored. Finally, the possibilities for further research are considered.

4.2 Discussion of the results: general findings

4.2.1 Research questions - main themes to emerge from the analysis of the transcripts

The initial two research questions looked at the criteria upon which the assessment of capacity to consent is based and the difference and/or similarities in the approach taken to the two vignettes. From the analysis three main themes emerged related to the assessment of capacity to consent to treatment, these were 'learning disability', 'seriousness of the situation' and 'understanding of the client's choice'. With regards to the assessment of capacity to consent to a sexual relationship two main themes emerged, these were 'learning disability' and 'understanding the current situation'. The third research question looked at the factors affecting the process of decision-making. Two themes affecting the assessment of capacity were apparent across both vignettes, these were 'assessment of capacity versus intervention/treatment' and 'rights of the individual versus protection from harm'. Finally, 'professional role' emerged as an important theme with regard to the final research question looking at differences between professional groups.

The similarities in the way in which participants approached the vignettes were considerable. The differences predominantly appearing to lie in, as one would expect, the specific nature of the two

vignettes. For example, differences in the specific information requested, i.e. with regard to risk in both situations or consideration of how to treat or support the client. These findings are explored further below.

4.2.2. Assessment of capacity to consent to treatment

The themes to emerge from the data concerning the assessment of capacity to consent to treatment reflect some aspects of the current accepted test of capacity in case law (English Department of Health and Welsh Office, 1993). For example, the need for the individual to understand the nature, purpose and effects of a proposed treatment, to assess the information and arrive at a choice, is apparent in the category, 'specific assessment of skills relevant to the situation'. However, considerable weight was given to understanding the reason behind the client's choice in terms of assessing capacity, something the law does not consider relevant (BMA/LS, 1995). The findings suggest some awareness of the difficulties in assessing capacity in people with learning disabilities that might lead the client to be seen as incompetent when they are in fact competent. For example, lack of experience in expressing views (Arscott, 1997), the way information is presented to clients (Appelbaum & Roth, 1982; Murphy & Clare, 1995) and increased likelihood of compliance (Clare & Gudjonsson, 1993). This was apparent in the categories, 'lack of decision-making experience', 'not informed or incorrect information given' and 'decision influenced by others'.

4.2.3 Assessment of capacity to consent to a sexual relationship

Participants found the assessment of capacity to consent to a sexual relationship more difficult to approach than the assessment of capacity to consent to treatment. This reflects the literature which is more limited in the guidance offered with regards to assessment of capacity to consent to sexual relationships (BMA/LS, 1995). The approach which the findings suggests was taken by

participants, was in line with common law, where the test of capacity to consent implies that the person understands what is proposed, its implications and is able to make a free choice (BMA/LS, 1995). This was apparent in the following themes and categories; ‘specific assessment of sexual knowledge’, ‘dynamics of the relationship/ client characteristics’ and ‘influence of others’.

4.2.4 Learning disability

There were a number of similarities in the criteria upon which capacity was assessed and in the processes affecting assessment across both vignettes. For example, ‘assessment of learning disability’ was equally apparent in the approach participants took to both vignettes. In the approach to both vignettes there was a sense that ‘assessment of learning disability’ entailed moving from obtaining global to more specific information, although in vignette two the focus for the assessment of learning disability was predominantly on specific skills and abilities related to the situation being considered. Where the client was thought to have the capacity to consent (based on ‘global assessment of abilities’) a deeper understanding of their level of skills and abilities was then requested. Assessment of skills and abilities in both vignettes concerned thinking about how informed the client was and how competent they were. However, in both vignettes whilst some participants were clearer than others, there did not appear to be any consensus on the level of understanding needed nor on how this should be assessed.

The findings of the study suggest that assessment of the client’s diagnoses (e.g. ‘global level of learning disability’) was not used alone by participants to assess capacity to consent, its inadequacy recognised by many. This is in line with the literature where the status or diagnostic approach to assessing capacity (e.g. Murphy & Clare, 1995), has been rejected in case law in England and Wales and by the Mental Health Act Code of Practice (Department of Health and

Welsh Office, 1993) as inadequate. However, assessment of 'global level of abilities' was made by most participants in both vignettes and was used as a means of excluding clients, who definitely would not be able to consent, from further assessment. Therefore, its role in assessment in this study needs to be considered carefully as it may be negatively affecting the thinking of professionals as suggested by Sinclair (1997). Using this approach thus may limit the opportunities available to people with learning disabilities to make decisions for themselves.

The role of diagnosis or status in the assessment of capacity did also however, appear to play a part in participants assessment of capacity in a more integrative way. For example, assessment of 'global level of abilities' leading participants to further question the client's capacity (Appelbaum et al. 1987; Hoggett, 1994; Law Commission, 1995). Following consideration of the client's status participants appeared to adopt a more functional approach, that is considering the skills and abilities needed by the client to make the decision in question. This approach, that is a combination of the diagnostic and functional approaches, reflects the current approach proposed in law (Law Commission, 1995; Scottish Law Commission, 1995). However, the analysis suggests that professionals also consider other factors when assessing capacity to consent and thus the approach taken is more complex than this.

Looking at how the functional approach was applied to the assessment of capacity in this study helps further identify how participants approached the assessment of capacity to consent. For example, participants were aware of the need to consider how informed the client was before capacity could be ascertained, which reflects the importance of the idea of informed consent (Sprung & Winick, 1989). In line with this, themes emerged from the transcripts of both vignettes relating to the 'influence of others', again this reflects the need for informed consent i.e. making a choice free from the influence of others (Appelbaum & Grisso, 1988; Murphy & Clare, 1997).

Analysis of the results suggested that participants do not always make decisions regarding the client's functional abilities upon the specific situation in question, but may base their decision on broader information or the ability of the client in other areas of their life past or present. This is particularly significant in that it differs to the view of capacity in the literature, where it is argued that capacity is not permanent but fluctuates according to the decision being made and should therefore be assessed for each individual decision (Hoggett, 1994; Wong, 1997). Finally, of particular interest the results suggested that there did not appear to be any consensus on the level of understanding needed for the client to be considered competent nor on how this should be assessed. This confusion is also apparent in the academic literature and law, where although it is becoming clearer and is currently being heavily researched (e.g. Wong et al. 2000), there is an apparent lack of consensus and guidance for professionals is limited (Morris et al. 1993).

4.2.5 Client choice

The risk to the client of the current situation and understanding of the client's choice were also important factors considered by professionals in both vignettes. In the first vignette, both these factors were however more dominant or apparent than in the second vignette. This appeared to be related to participants' initial perceptions of the client's choice. In the first vignette the client's choice was not seen as the choice most people would make and could potentially put the client at risk. In the second vignette, the client's choice was seen as a safe choice and thus the immediate risk to the client was likely to be minimal. Client choice therefore appears to be central in assessment of capacity to consent.

Relating this to the current literature thus again expands on our understanding of the approach participants took to the assessment of capacity to consent. The findings of the study suggest that the approach taken to the assessment of capacity also involves consideration of the client's

choice, its understanding in terms of its normality or rationality and its consequences. This is in line with the outcome approach proposed in the literature, which bases assessment of capacity on a client's decision and the consequences of that decision (Law Commission, 1991; Stanley, 1987; Venesy, 1994). Assessment of outcome by participants was not used in isolation but in combination with the functional approach. This is an approach to the assessment of capacity suggested by Jackson (1994) and Roth et al (1977).

The importance of risk was considerable in the way that the study's findings suggest participants' approached the assessment of competency. However, the results suggest that where risk was considered great, consideration of the client's functional abilities was either given greater importance or dismissed in favour of best interests. Thus, assessment of functional abilities was either more thorough or no longer seen as applicable, the risk to the client being the deciding factor in assessment of the client's competency. The literature in this area criticises the outcome approach and the combination of the outcome and functional approaches (e.g. Hoggett, 1994; Gunn, 1994). The outcome approach being firmly rejected in case law (Kennedy & Grub, 1994). The difficulties with which this approach has been said to present were also apparent in the study's findings. For example, the appropriateness of the client's choice was considered differently by different participants, thus being a consideration of a professional's view as to when the individual's decision should be accepted rather than an assessment of competence (Culver & Gert, 1990; Venesy, 1994).

4.2.6 Factors affecting the process of assessment of capacity to consent

Not only were there important similarities in the criteria upon which participants were basing their assessment but also in the factors affecting the process of assessment of capacity to consent. For example, throughout both vignettes there appeared to be a struggle between the need to

assess competency and the need to intervene or treat. Linked to this was also a struggle between the need to consider the rights of the client to make their own choice and the right of the client to be protected from harm, that is for the professional to act in the client's best interests. Through analysis of the transcripts some participants appeared aware of these dilemmas, whilst others appeared more clear or settled in their role or approach when faced with the situations presented.

The two aspects outlined above appeared in the findings to represent a continuum of responses from participants. For example, some participants predominantly focused on the assessment of competency, others on intervening and treatment, most assessing both aspects with some emphasising one more than the other. Similarly, some participants emphasised the right of the client to choose and thus assessment of capacity, others the right of the client to protection from harm, most however falling somewhere along this continuum. These difficulties reflect the central issue in the assessment of capacity i.e. the balance between the right to self-determination and the right to protection from harm (Kaplan et al. 1988). The assessment of the presence or absence of capacity having major effects on people with learning disabilities (Wong et al. 1999).

The two overriding factors identified through analysis as affecting the decision-making process reflect concerns raised in the literature regarding the consideration given to the rights of people with learning disabilities by professionals and carers (Murphy & Clare, 1995). In many instances the approach taken by participants was in favour of treatment or protection, decisions being made for clients, a concern raised by Arscott (1997) in her critique of approaches to assessment of capacity to consent. The processes identified may reflect the uncomfortableness and difficulty as a professional accepting the decision of an individual deemed competent, if the decision they are making is not seen as in their best interests, again a concern raised by Arscott (1997). These decisions thus clearly raise ethical and moral dilemmas for professionals (Arscott, 1997). The

difficulty these decisions present may also reflect the lack of guidance for professionals inevitably leading to subjective decisions (Glass, 1997) and/ or the need to act professionally given the increasing focus on litigation, therefore leading the professional to take the safer decision. However, this means that those clients deemed as competent, may not be allowed to make mistakes or take risks something most individuals value. The difficulties with which the findings suggest professionals struggle with when faced with these decisions thus have major implications for the welfare of people with learning disabilities.

4.2.7 Professional role

Differences also apparent in the way participants viewed their role in the assessment of capacity to consent inevitably affected the way in which they approached the vignettes. However, the main themes identified in the findings were shared across all participants. Hence, professional role did not appear to affect ideas of what participants would want to be assessed, but more in-depth information in how this might be done.

The findings in relation to professional role suggest that no one professional group present a coherent strategy for obtaining informed consent. Viewing the assessment of capacity to consent as multidisciplinary may be one way of sharing the responsibility of the uncomfortableness of the decision concerning the dilemmas presented above. Again this may also reflect the lack of guidance available to professionals in making decisions related to capacity (Glass, 1997).

4.3 Discussion of the results: theoretical implications

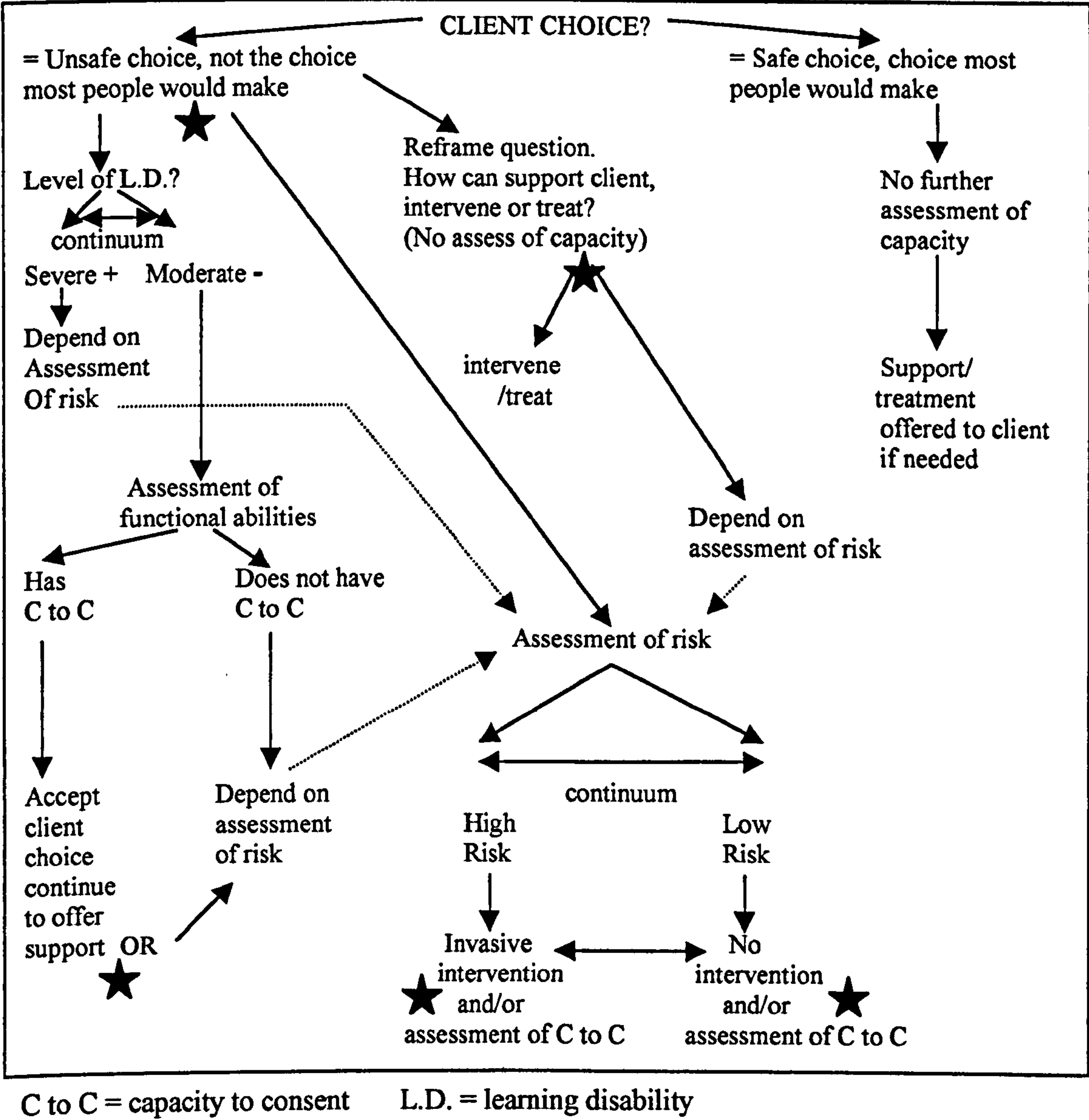
The findings of the study suggest that the way in which the assessment of capacity to consent is approached is complex, drawing on aspects of several of the different approaches outlined in the

literature. For example, the status, outcome, functional and integrated approaches (Arscott, 1997; Murphy & Clare, 1995; Wong, 1997). The findings further suggest that the assessment of competency in people with learning disabilities is mediated by a number of factors which affect the process of decision-making. Figure 1. on the following page is a tentative model of how capacity to consent is assessed in practice based on the study's findings.

The model in figure 1. suggests that where there is an issue regarding the competency of a client to make a decision, a professional would ask a number of questions before deciding to undertake an assessment of capacity to consent. The initial question asked would be related to the client's choice, which if seen as unsafe or not the decision of most people, would lead to further assessment. However, the direction the assessment then takes is likely to depend on the views of the professional with regard to 'the right of the client to make their own choice versus the right of the client to protection from harm' and 'assessment of capacity versus intervention/ treatment'. These were the factors found in this study to affect the decision-making process. The ★ symbol indicates the points at which these factors appear to affect decision-making. For example, having determined the client's choice as unsafe, the professional may decide to either assess the client's competency, establish the level of risk to the client or look at how to support or treat the client, depending on their view of the factors outlined above.

The literature with regard to capacity to consent does not reflect the complexity with which the findings of this study suggest capacity is assessed in practice. The current focus of research in this area on the functional approach and the measurement of functional abilities (e.g. Wong et al. 2000) considers the assessment of capacity as though it were in a vacuum. The results of this research suggest that in practice this is not the case, the factors affecting the process of decision-making having a major impact on the assessment of competency. This finding reflects the views

Figure 1. A tentative model to represent how capacity to consent is assessed in practice



of Wong (1997) who argues that the assessment of competency is not a matter of science but one of common sense and understanding. This also reflects the views of Morris et al. (1993) that the criteria on which the assessment of capacity is based only provide a foundation for what is a subjective decision which requires professionals to balance the right to self-determination with the right to protection from harm. Hence, the criteria and the processes upon which the assessment of competency is based need equal consideration.

4.4 Discussion of the method

4.4.1 Sampling issues

The aim of qualitative research is not to make generalisations, but to deepen our understanding of the process being explored, in this case how capacity to consent is assessed in practice. The professional groups selected to take part in the study were seen to reflect those professionals who were most likely to take part in decision-making related to assessing capacity to consent in practice. This was verified by participants, all of whom had experience of assessing capacity to consent, expressed an interest in taking part predominantly because of these experiences and most of whom, when asked, viewed decisions related to competency as multidisciplinary in nature. Therefore seeking the subjective experience of a range of professionals was seen as important to the representativeness of the views about the process being uncovered.

However, through the research it became clear that other professional groups (not interviewed) are also involved in the assessment of capacity, to which SLT was most commonly referred. Thus, the study does not include the view of any member of this profession and therefore may not have picked up on important themes related to assessing competency or may not be giving adequate weight to a particular process or method of assessment, limiting to some extent the study's representativeness. In thinking about this further, it is also important to acknowledge the influence of the service context and policies on the way in which a professional might approach the task under consideration. In this research professionals were recruited from a limited number of services. That being said, the study found a high level of continuity in themes identified across these services, suggesting that the experiences of participants did not differ substantially. However, in the study's attempt through sampling to realistically reflect how capacity is assessed in practice it is important to note that it is also limited.

4.4.2 Interview design

The study's design appeared to be a useful method for exploring the way in which professionals approach the task of assessing capacity to consent without unduly influencing how they might do this. By asking participants to generate questions about the case vignette the interviewer was not predetermining the direction the participant might take. The interviewer tried to provide consistent information to similar questions across participants. However, whilst for most participants the interview process worked well, a few found it more difficult. This either appeared to be because they were particularly experienced in this area and wanted to reflect on the difficulties of assessing capacity to consent or because they found it difficult to know where to begin and therefore wanted further prompts as to the issues. In these cases the interviewer was in the position of wanting to explore these difficulties, seeing them as of value to the range of subjective experiences to be uncovered, but at the same time not wanting to unduly influence these participants and thus affect the results. The interviewer therefore, whilst providing further information or in trying to keep the participant on task, tried to avoid guiding or leading questions. Inevitably therefore the structure provided by the interview was both helpful and on a few occasions limiting.

Given that the interview presented participants with a somewhat unusual task, it may have been helpful to have incorporated a practice vignette. However, this was decided against given the time it would have added to the interview length. It may also have been valuable to have varied the order in which the vignettes were presented to participants in order to counter balance the effects of learning on how participants approached the second vignette. It is thus important to view the study's findings in light of this.

4.4.3 Use of case vignettes

The case vignettes were designed to present participants with a dilemma in which there was no easy answer and where any decision concerning capacity was unlikely to be made on any one determining factor. In practice, they gave rise to a wealth of information about how professionals assess capacity to consent thus effectively meeting their need. However, the findings are specific to the vignettes used and whilst an attempt was made in their design to encompass a range of factors thought to affect capacity to consent, one cannot know what other case vignettes may have given rise to. It is therefore important to consider the study's findings within these limitations.

4.4.4 Issues of reliability and validity

A number of measures were used to establish the reliability and validity of the study's findings. All participants were asked to comment on the results of this research, but only two replied. The comments received were essentially positive. However, from this limited sample of views it is difficult to assess how representative the study's findings were of participant's views on the assessment of capacity to consent. Looking at the other measures of reliability and validity undertaken provides a clearer view of the study's findings concerning this.

4.5 Clinical and service implications

The assessment of capacity to consent has major effects on the welfare of people with learning disabilities. The study's findings suggest that professionals struggle with the complexity that these issues raise and lack a coherent understanding of the current literature. This has considerable clinical and service implications.

Adequate teaching and training for professionals needs to be provided to offer guidance on how capacity to consent can be assessed drawing on both the legal and academic literature in this area. The findings of this study suggest that the participants in this study had received limited training on this topic (see Table 1.). An open forum for professionals to discuss and think about the balance between the right to make decisions for one self and the right to protection from harm needs to be available. This requires support through service policies that reflect the current literature in this area and place a high value on the right of people with learning disabilities to make decisions about their own life including for example, the right to take risks or make mistakes. Equally, where a client is deemed not to have the capacity to consent, professionals need adequate guidance on the application of duty of care and best interests.

There is some evidence from this study's findings that situations related to client choice are not always perceived as related to capacity. Professionals therefore also need to take responsibility for updating themselves on the literature in this area, as well as reflect on the process of assessing capacity to consent, their understanding, beliefs and views. Further to this professionals need to consider how the way in which they approach the assessment of capacity either limits or enhances the welfare of the clients, given that people with learning disabilities are dependent on professionals for this.

4.6 Further research

The findings of the study raise a number of questions that could be explored in future research and thus further our understanding of the area. For example, a substantial amount of attention has now been paid to the assessment of capacity, with current emphasis on capacity to consent to treatment. However, the findings of this study suggest that there is a considerable gap between

theoretical knowledge and current practice. Research into the design and evaluation of a teaching or information package maybe helpful in lessening this gap, expanding the knowledge of professionals and raising awareness of the importance of considering competence with regards to the welfare of people with learning disabilities. Current research has predominantly focused on the criteria upon which assessment of capacity to consent should be made, paying little attention to the factors affecting the assessment of competency, which as this research suggests can substantially affect the assessment of capacity by professionals. Research looking at attitudes towards the rights of people with learning disabilities and/or how professional attitudes affect practice in this area may enhance our understanding of the way in which different processes contribute to professional judgement concerning assessment of capacity. Finally, the study also raised questions about decisions regarding best interests, further research may be helpful in drawing up more specific guidelines for professionals with regards understanding and applying the concept of best interests.

4.7 Conclusions

The study found that the approach taken to the assessment of capacity to consent to treatment and capacity to consent to a sexual relationship by participants were similar both taking into account: client choice, level of learning disability, the client's functional abilities and the risk to the client. Differences in the approaches taken to the two vignettes lay in the specific details sought with regard to, for example, what factors were considered important in the assessment of risk. Two overriding factors were found to affect the decision-making process, these were related to the right to self-determination versus the right to protection from harm and assess of capacity versus the need to treat. Lastly, participants' views on differences in professional role emerged as an important theme. In summary, the study's findings suggest that the process of decision-making in

practice is complex. This complexity appearing to reflect the difficulties with which the assessment of capacity presented participants and the lack of guidance currently available to professionals in this area.

In conclusion, the study's findings provided a vast amount of information related to the assessment of capacity to consent to treatment and capacity to consent to a sexual relationship. This builds on our understanding of how current ideas which have arisen out of the literature in this area, relate to the assessment of competency in practice. Thus in essence the findings of this study provided an in-depth exploration of the assessment of capacity from the perspective of the professional, expanding on our knowledge in this area, as well as identifying areas in need of further exploration.

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5th October, 1999.

Dear Ms. Bourne,

Re: Research Proposal - Determining Capacity to Consent in People with Learning Disabilities

Thank you for sending me details of your research proposal. I apologise for the delay in replying.

I can confirm that we are happy for you to proceed and for staff in our Service to be interviewed.

Yours sincerely,

Associate Director
Learning Disability Services

WCH:MMH

06 September 1999

Dear Ms Bourne

RE RESEARCH PROPOSAL – DETERMINING CAPACITY TO CONSENT IN PEOPLE WITH LEARNING DISABILITIES

Further to your letter dated 24 August 1999. We are interested in assisting you with your research.

Could you please ring me to arrange a time to come to a team meeting to discuss your proposals further.

Yours sincerely

PP
Service Manager,
Special Needs Adults - Team

APPENDIX 2.

PARTICIPANT DETAILS

interview number

1. Professional status: (please tick)
- Care Manager
Community Nurse
Psychiatrist
Psychologist

2. Age:

3. Sex: (please tick)
- Male
Female

4. How many years have you worked in services for people with learning disability?

5. How often do decisions related to capacity to consent occur in your clinical practice? (please tick)
- Weekly
Monthly
Six Monthly
Yearly

6. Which professionals make decisions related to capacity to consent in the team in which you work?.....
.....
.....
.....
.....

7. What training have you received related to ‘consent’?
.....
.....
.....
.....
.....
.....

APPENDIX 3.

15 September 1999

Dear Ms Bourne

Determining capacity to consent: an exploration of decision-making by professionals in learning disability services

Thank you for submitting the above study.

As there would not appear to be any ethical concerns I do not feel that presentation of your study to the Local Research Ethics Committee would be necessary.

Yours sincerely

PP -
Chairman
Local Research Ethics Committee

05 October 1999

Dear Ms Bourne

Re: Determining Capacity to Consent: An Exploration of Decision Making by Professionals in Learning Disability Services

Thank you for your letter of the 28th September 1999. All research involving NHS patients, staff or resources requires review by a research ethics committee. This usually involves submitting an application form to the Committee. However, on the basis of the information supplied in your letter and the accompanying protocol, I am able to provide provisional ethical approval for this work acting on Chairman's Action. This decision will be ratified by the full LREC when it meets on the 13th October 1999. You should assume that this decision is ratified unless the Committee raise any further issues in which case I will write again.

I would remind investigators that our approval is conditional. Approval may be withdrawn if the Committee review the study and are concerned about the conduct or consequences of the work. The Committee require that the investigator inform them of any changes to the protocol, or any serious adverse events during the work, and expect to be given a copy of the final research report.

I wish you well in your research endeavours.

Yours sincerely



Ms K Bourne
97 Pathfield Road
Streatham
London SW16 5PA

11th January 2000

Direct line 01892 507668
Direct fax 01892 507660
E-mail l.thompson@salomons.org.uk
Our Ref LT/lr/075/2000/KB

Dear Katie,

Re: Ethics Approval – Determining Capacity to Consent; An Exploration of Decision Making by Professionals in Learning Disability Services

Thank you for your letter of 4th January 2000 with enclosures.

The Panel note that you have given very good and careful consideration of the points raised in our letter dated 13th December 1999 and is pleased to confirm full ethical approval for your research project.

We look forward to seeing the results and hope you enjoy the research.

Yours sincerely,

Professor A. Lavender
Chair of Ethics Panel

c.c. Dr C. Hogg
Mr N Armstrong

APPENDIX 5.

SERVICE REPORT

RESEARCH PROJECT

**ASSESSING CAPACITY TO CONSENT IN PEOPLE WITH LEARNING
DISABILITIES**

Katie Bourne
Psychologist in Clinical training
South Thames (Salomons) Training Programme
17/7/00

INTRODUCTION

Firstly, this report was written with the aim of providing a summary of the research completed. The reader is referred to the copy of the full dissertation for further information on the study's design and findings. Secondly, it was written with the aim of highlighting the literature in this area likely to be of interest to professionals, when making decisions related to the assessment of capacity to consent to treatment and to a sexual relationship. A reference list is also attached.

1. BACKGROUND INFORMATION

1.1 Capacity to consent in people with learning disabilities

Current law states that all adults have the capacity to make decisions affecting their lives, unless there is evidence to the contrary, and should be encouraged and enabled to do so (The Law Commission, 1995). The determination of the presence or absence of capacity has major implications for choice and self-determination. This is particularly evident in the field of learning disabilities, where historically adults have not been seen to have the capacity to make decisions affecting their own lives (Fennell, 1996). As this view has changed, (Murphy & Clare, 1997) assessment of capacity to consent in people with learning disabilities has become the focus of considerable attention. Whilst assessing capacity may be related to any number of situations. Of most relevance with regards to clinical decision-making, is the academic literature and law related to the assessment of capacity to consent to medical interventions and capacity to consent to sexual relationships.

1.2 What do we mean by capacity to consent?

Assessing capacity requires a means of distinguishing those persons who can make decisions and whose choices should therefore be respected, from those who require protection from harm and who therefore need choices to be made for them (Wong, Clare, Gunn & Holland, 1999). The law states that once a person has reached adulthood they are assumed to have legal capacity unless there is evidence to the contrary (BMA/LS, 1995). The concept of capacity has evolved to include the concept of informed consent. Informed consent is argued to have three main components (Appelbaum & Grisso, 1988). These components are: possessing sufficient information relevant to the decision being made, having the capacity to make that decision and to understand the consequences, and making the decision voluntarily free from coercion. Capacity must therefore be assessed before informed consent can be sought (White, 1994).

1.2.1 Capacity to consent to treatment

Current legal definitions of capacity to consent to treatment can be found in case law and in The Mental Health Act Code of Practice (English Department of Health and Welsh Office, 1993, para. 15.10). In case law the current accepted test of capacity requires an individual to; 1) sufficiently understand the nature, purpose and effects of a proposed treatment and retain the treatment information; 2) believe it; and 3) assess the information in arriving at a choice. The right to self-determination exists regardless of the outcome of the decision or the diagnostic group to which the patient may belong (Wong, 1997). The MHA code of practice suggests that to be able to consent an individual must possess an 'adequate knowledge of the purpose, nature, likely effects and risks of (the) treatment including the likelihood of its success and any alternatives to it' (p.55). However, this only applies to people with a mental disorder as defined by the Act and it is unclear what criteria should be used to assess 'adequate' knowledge.

Health care professionals cannot legally examine or treat any person without his/her valid consent (BMA, 1995) and this consent must be provided by the person being treated (Murphy & Clare, 1995). This right to autonomy exists whether the reasons for making the choice are rational, irrational, unknown or even non-existent (BMA/LS, 1995). The right to self-determination is only seen as meaningful if the person is appropriately informed, is free to make decisions from coercion and has the ability or capacity to do so (Wong et al. 1999). The exception here is if the person is being treated under the provisions of Part IV of the Mental Health Act (1983).

Where a person is seen as unable to consent, treatment may only be given in exceptional circumstances involving either necessity (the meaning of which is unclear, Mackay, 1990) or an emergency. This may mean that people with learning disabilities do not receive the treatment they require because of uncertainties about its lawfulness (MENCAP, 1989). However, The House of Lords (1990), in a more recent ruling stated that those providing treatment for someone unable to give consent would not be subject to accusations of unlawful actions provided that they acted in the person's best interests and in accordance with responsible and competent body of relevant professional opinion (Murphy & Clare, 1995). Thus, when acting in terms of the client's best interests professionals should consider the least restrictive means of supporting that client.

1.2.2 Capacity to consent to a sexual relationship

In England and Wales, a sexual relationship between two people is lawful if both partners are able to consent and have given their consent (Gunn, 1996). In law women aged 16 years and above are seen as able to consent to a heterosexual or homosexual relationship. For men entering a heterosexual relationship there is no lower age of consent. Whilst for men entering a homosexual relationship only those aged 16 years and above are deemed able to give consent. With few exceptions, people can consent to sexual activity and therefore rights must not be infringed upon (BMA/LS, 1995). The law only becomes involved where there is concern that the person did not consent, hence questions are not raised about capacity but incapacity.

The focus of current law is on protection from abusive relationships (BMA/LS, 1995). Where there is sexual activity and consent is disputed a sexual offence may have taken place. Whilst a professional may be asked whether a person could have given their consent, that is did they have the capacity to make the decision, whether or not they did give their consent in the situation in question is a matter for the court to decide (Murphy & Clare, 1997). This focus on protection from abuse and exploitation is also often reflected in local service guidelines (Booth & Booth, 1992). In such guidelines although it is frequently asserted that people with learning disabilities have an equal right to sexual expression, guidance is mainly offered on what should be done if abuse becomes known, whilst little help with regards to what constitutes consent is given (Murphy & Clare, 1995).

Entering a sexual relationship does not require any formal test of capacity (BMA/LS, 1995). Decisions regarding sexual relationships must be taken by service users personally. They are not within the decision-making powers of carers (Law Commission, 1993b) and nobody can be told to have a sexual relationship. The reason why consent is given is also not considered relevant in law, thus enabling people to consent for all sorts of reasons. People may therefore consent for reasons that include sexual gratification, affection, duty, money, physical closeness, physical comfort or fear (Murphy & Clare, 1995). Exactly what constitutes 'consent' to sexual activity is thus unclear. There is no requirement that people engaged in sexual activity should exercise informed consent of the kind required for medical treatment. There is thus no requirement under law that people demonstrate that they understand the nature of sexual activity, the risks, benefits or the alternatives to sexual activity.

However, in common law the test of capacity to consent to sexual relations implies that the person understands what is proposed, its implications and is able to make a free choice (BMA/LS, 1995). Strictly applied this means that a person needs to have good sexual knowledge and good social and communication skills. In practice where a sexual relationship involving a person with a learning disability has begun or appears likely, Murphy and Clare (1995) suggest carers and professionals should consider the following issues; 1) is there a major imbalance of power between the two individuals and if so is there a greater risk of an abusive relationship, 2) is the sexual relationship rewarding in itself or is one person offering the other inducements, 3) if the relationship is heterosexual do both partners realise that pregnancy can result, 4) if the relationship is heterosexual do both partners know what contraception is and how to use it, 5) do both partners understand the risk of sexually transmitted diseases and know how to engage in safer sex and 6) if pregnancy is possible have both partners been given adequate access to genetic counselling and been informed and understood issues related to parenting.

1.3 Approaches to the assessment of capacity to consent

In the literature, three broad approaches to assessing capacity have been distinguished. These are based on; 1) the outcome of the decision or choice made by the patient, 2) the patient's status or diagnosis and, 3) the patient's functional abilities (Presidents Commission, 1983; Weisstub, 1990; Hoggett, 1994). Some have suggested that an integration of approaches would be more applicable (Weisstub, 1990; Hoggett, 1994). However, whilst all are argued to be problematic (Wong, Clare, Gunn & Holland, 1999; Gunn, 1994; Carson, 1993), the functional approach has received most support (Law Commission, 1995). Consequently the academic literature in this area has focused on exploring; 1) the functional abilities considered relevant to decision making and, 2) the assessment of these abilities in practice (Law Commission, 1995).

1.3.1 Psychological tests of capacity to consent from a functional perspective

There have been few psychological tests developed for assessing capacity in practice and rarely for use with people with learning disabilities, those that are available have been developed from a functional perspective and with regard to consent to medical treatment. There is no universal agreement on which functional abilities contribute to the assessment of capacity, although, there is a consensus that the following abilities are important. These are: 1) the ability to communicate a choice; 2) understanding the relevant information; 3) retaining the information; 4) appreciating its relevance to oneself and; 5) being able to weigh up the risks and benefits and rationally

manipulate the information to arrive at a choice (Appelbaum & Grisso, 1988; Weisstub, 1990; Law Commission, 1995; Berg, Appelbaum & Grisso, 1996; Wong et al. 2000). These tests are in essence standards of competence, allowing autonomy to be maintained or forfeited (Kaplan et al. 1988).

A number of psychological tests have been developed for use in clinical practice with people with mental health problems and people with dementia. This for example, includes The Knowledge and Understanding Test (Annas & Densberger, 1984), The Competence Interview (Scaright, 1992) and The MacArthur Treatment Competence Study Assessment Instruments (Appelbaum & Grisso, 1995). Tests to be used with people with learning disabilities are in general lacking. Having said that, of most significance is the assessment of capacity to consent specifically for use with people with learning disabilities developed by Morris, Niederbuhl & Mahr (1993). The test is based on three vignettes related to treatment, which require informed consent. In each vignette the underlying problem and a description and review of the proposed treatment is presented to the client, followed by a series of questions to test the individual's ability to consent to that treatment. However, the measure is argued to be unnecessarily stringent, does not take into account the difficulties experienced by clients when faced with treatment decisions and thus people who may be able to make decisions for themselves would not be considered able to do so if this test were applied (Arscott, 1997). Arscott, Dagnan, Stenfert (1999) have attempted to simplify this measure with the aim of making it easier for people to understand the information presented. However, as yet this test has not been adapted for use in clinical practice. Thus, whilst it is unlikely that tests will be used as the sole predictor of competence in people with learning disabilities, they are seen as providing useful guidance for professionals (Arscott et al. 1999). Given the difficulties there are in assessing capacity to consent to treatment, Wong et al. (1999) propose a framework in the format of a decision-making tree to assist professionals in the process of making such assessments.

A number of sex education training packages are available for working with people with learning disabilities (Croft & Brown, 1994). When thinking about the assessment of capacity these packages could be used before and after training to assess a person's understanding. There are also a number of tests of sexual knowledge, some of which include social interaction questions as well as questions about sexual facts (e.g. Fisher, Krajicek & Borthick, 1973; Wish, McCombs &

Edmonson, 1979; Bender, Aitman, Biggs & Haug, 1993). However, there are no specific assessments of capacity to consent for use in these circumstances.

1.4 Professional decision-making and the assessment of capacity to consent

The law related to assessing capacity to consent is at present complex and guidance for health care professionals is lacking (White, 1994). It is argued that in practice, professionals employ an eyeball method to determine capacity, with decisions being made subjectively based on intuition and instinct (Law Commission, 1991). It is further argued that whilst criteria for assessment of capacity are important, they provide no more than a foundation for what is argued ultimately to be a subjective, moral decision, which requires professionals to balance the right to self-determination, with the right to protection from harm (Morris, Niederbuhl & Mahr, 1993). If criteria used to assess capacity are too strict or too lenient, rights are infringed upon. It is argued, that where the line is drawn will vary across situations and depends largely on the risks, benefits, complexity and sensitivity of the situation (Morris, Niederbuhl & Mahr, 1993). Competence is a social construct influenced by the values of society and the professional completing the assessment (Glass, 1997). Glass (1997), argues that whilst it may not be possible to eliminate the influence of values held, their impact should be made explicit so that we may judge openly whether they are legitimate.

1.5 Aim of the study

Assessing capacity is a complex task and at present little is known about how current ideas which have arisen out of the literature with regards to competency relate to practice. Little is known about how decisions about capacity are approached by professionals although some (e.g. Sinclair, 1997; Arscott, 1997; Glass, 1997) have speculated about the difficulties that this might present. The research that has been done in this area appears to have developed out of the legal literature on the assessment of competency and thus our current understanding of competency is heavily dependent on legal findings.

Therefore the aim of this study was to explore how capacity to consent in people with learning disabilities is assessed by professionals in practice. To look at both the criteria upon which capacity is based and the factors affecting the decision-making process with regards to capacity to consent to treatment and capacity to consent to a sexual relationship. Secondary to this, the

study aimed to explore whether decisions made relating to capacity are made differently by different professional groups.

2. METHOD

19 professionals; 5 psychologists, 5 care managers, 5 community nurses and 4 psychiatrists were recruited from staff working with people with learning disabilities in two local NHS Trusts and one Social Services Department.

The interview method employed involved the use of two case vignettes one related to the assessment of capacity to consent to treatment and the second related to the assessment of capacity to consent to a sexual relationship. Participants were initially presented with a small amount of information related to the first vignette and then requested to ask questions to elicit more detail about the case vignette they had been given, in order to assess the client's capacity to consent. Once the participant had asked as many questions as they wanted, the interviewer went back over the participant's questions, exploring with them their thinking and reasoning behind the questions asked. The same process was then completed again for the second case vignette. Thus, the study was designed to explore both the criteria upon which participants based their assessment and the factors affecting the decision-making process.

The transcripts were then analysed using interpretative phenomenological analysis (IPA). IPA is a qualitative method of analysis, which aims to explore in detail the participant's view of the topic under investigation (Smith, Jarman & Osborn, 1999).

3. FINDINGS AND IMPLICATIONS

3.1 Research findings

In summary, the study found that the approach taken to the assessment of capacity to consent to treatment and capacity to consent to a sexual relationship by participants, were similar. The assessment of capacity in both the assessments took into account: client choice, level of learning disability, the client's functional abilities and the risk to the client. Differences in the approaches taken to the two vignettes lay in the specific details sought with regard to, for example, what factors were considered important in the assessment of risk. The study also concluded that there were two overriding factors, 'the right of the client to make their own choice versus the right of the client to protection from harm' and 'assessment of capacity versus intervention/ treatment'

have a major impact on the decision-making process across both vignettes. Lastly, whilst the approach taken by participants from different professional groups was similar, participant's views on the differences in professional role emerged as an important theme. In summary, the study's findings suggest that the process of decision-making in practice is complex. This complexity appearing to reflect the difficulties with which the assessment of capacity presented participants and the lack of guidance currently available to professionals in this area.

3.2 Clinical and service implications

The assessment of capacity to consent has major effects on the welfare of people with learning disabilities. The study's findings suggest that professionals struggle with the complexity that these issues raise and lack a coherent understanding of the current literature. This has considerable clinical and service implications.

Adequate teaching and training for professionals needs to be provided to offer guidance on how capacity to consent can be assessed drawing on both the legal and academic literature in this area. The findings of this study suggest that the participants in this study had received limited training on this topic. An open forum for professionals to discuss and think about the balance between the right to make decisions for one self and the right to protection from harm needs to be available. This requires support through service policies that reflect the current literature in this area and place a high value on the right of people with learning disabilities to make decisions about their own life including for example, the right to take risks or make mistakes. Equally, where a client is deemed not to have the capacity to consent, professionals need adequate guidance on the application of duty of care and best interests.

There is some evidence from this study's findings that situations related to client choice are not always perceived as related to capacity. Professionals therefore also need to take responsibility for updating themselves on the literature in this area, as well as reflect on the process of assessing capacity to consent, their understanding, beliefs and views. Further to this professionals need to consider how the way in which they approach the assessment of capacity either limits or enhances the welfare of the clients, given that people with learning disabilities are dependent on professionals for this.

3.3 Conclusion

The study's findings provided a vast amount of information related to the assessment of capacity to consent to treatment and capacity to consent to a sexual relationship. This builds on our understanding of how current ideas which have arisen out of the literature in this area, relate to the assessment of competency in practice. Thus in essence the findings of this study provided an in depth exploration of the assessment of capacity from the perspective of the professional, expanding on our knowledge in this area, identifying areas in need of further exploration.

**DETERMINING CAPACITY TO CONSENT; AN EXPLORATION OF DECISION
MAKING BY PROFESSIONALS IN LEARNING DISABILITY SERVICES
INFORMATION SHEET AND CONSENT FORM**

Researcher : Katie Bourne
(Psychologist in Clinical Training)

Supervisor: Anthea Sperlinger
(Clinical Psychologist)

Telephone contact number: 01892 507666

Outline Explanation of the study

Professionals are often faced with difficult dilemmas related to determining capacity to consent. At present, the literature available to aid professionals with such decisions is limited. There are no agreed assessment criteria and the law is both complex and vague. Yet, such decisions have a major impact on the rights and the lives of people with learning disabilities.

In this study, to obtain a better understanding of how professionals determine capacity to consent and to make more explicit the factors affecting such decisions, professionals with experience of making decisions related to capacity will be interviewed. The interviews will revolve around two case vignettes. One related to the capacity of a client with a learning disability to consent to a medical intervention and the second related to the capacity of a client with a learning disability to consent to a sexual relationship. Before beginning the interview participants will be given a short questionnaire regarding demographic details and their experience in this area.

Interviews are anticipated to last approximately one hour and will be divided into two parts. In part one, participants will initially be given limited details of a case vignette and instructions to ask the interviewer questions about the case, in order to elicit further details about the client in the vignette and determine the client's capacity to consent. In part two, the interviewer will go back over the questions the participant asked to explore with the participant their thinking and reasoning behind these questions. This will be repeated for each of the two case vignettes.

Interviews will not involve participants talking about or referring to clients they work or have worked with. Each interview will be taped. Individual interviews will remain confidential and anonymous throughout the course of the research. Participation in the study is voluntary. Upon full completion of the research all transcripts and tapes of interviews will be destroyed.

When the research is finished, a copy of the dissertation will be made available to the service and a shorter report provided discussing issues raised by the study, likely to be of interest to the service.

Name _____

Work address _____

I hereby consent to take part in the above study, the nature and purpose of which have been explained to me. Any questions I wished to ask have been answered to my satisfaction. I understand that I may withdraw from the study at any stage without giving a reason for doing so.

SIGNED (Participant) _____ **Date** _____

INSTRUCTIONS FOR PARTICIPANTS

At the beginning of the interview you will be given a small amount of detail about two case vignettes. The first will be about a client with a learning disability who needs to undergo a medical intervention, the second will be about a client with a learning disability who is likely to become involved in a sexual relationship. In both cases, you will be asked to determine the client's capacity to consent.

The interview will be divided into two parts. 30 minutes will be given for each case vignette – roughly 15 minutes for each part of the interview.

PART 1.

After you have received details about the first vignette, you will be requested to ask the interviewer questions in order to obtain more detail about the case so that you can determine the client's capacity to consent. The interviewer will provide further details about the case as you ask questions. You may ask as many questions as you want.

You will need to keep a brief note of the questions you ask and their answer, for use in part 2 of the interview.

PART 2.

The interviewer will go back over the questions you asked, exploring with you, your thinking and reasoning behind the questions asked. At the end of part two you will be asked if you thought the client had capacity to consent and briefly summarise what you based this decision on.

APPENDIX 8.

CASE VIGNETTE 1.
CAPACITY TO CONSENT TO A MEDICAL INTERVENTION
(Initial information for participants)

Bill has been complaining of a sore mouth, it is suspected that he will need some of his teeth removed due to infection.

You have been asked to assess Bill’s capacity to consent to dental treatment.

CASE VIGNETTE 1. CAPACITY TO CONSENT TO A MEDICAL INTERVENTION

(Interviewer's details)

Bill

Age

58

Brief history

Bill has been having problems with his teeth for some time. Bill likes sweet food but dislikes washing his teeth and will often refuse. This has resulted in continuous problems with his teeth and gums (decay). Bill received dental treatment approximately 2 years ago, which he detested and required a lot of support and encouragement to undergo, but did agree to undergo. This was from a specialist in learning disability dentistry. He did not need sedation, dental treatment was received under local anaesthetic. He is otherwise fit and healthy and has had no other previous hospital treatment.

Current problem/ Cause of concern

Bill's teeth appear to be causing him increasing problems again. He cannot eat on one side of his mouth and now regularly asks for painkillers. Over the last few weeks he has become quieter, less interested in activities and has become a bit more frustrated occasionally throwing things. The dentist now thinks he may need tooth/teeth removed. Not sure what the dentist is proposing to do this time. The staff are concerned to see Bill in pain.

No weight loss at the moment. Staff report sleeping to be OK. He is not on any other painkillers.

Current circumstances

Bill lives in a residential house (joint health and social services) with nine other clients. He enjoys helping staff and generally pottering about the house. He carries a bag with him, which he collects things in and then likes to show others. Bill attends a local day centre for people with learning disabilities three days a week, where he is described as 'friendly but nervous'. Bill enjoys taking part in woodwork and dancing.

Bill's parents died several years ago. He does not have an advocate.

What does Bill want?

When staff attempt to talk to Bill about his teeth, he will change the subject. When staff suggest he needs to go to the dentist he responds 'no' saying tablets (painkillers) make it better.

Learning disability

Bill has a moderate learning disability and Downs Syndrome. He has some speech difficulties finding it difficult to express himself. Conversation with Bill is general repetitive and limited. His receptive understanding however, is thought to be better. With prompting, Bill is able to do most everyday routine tasks himself. He requires supervision with less familiar or more complex tasks. Bill does not go out alone, becoming easily anxious in difficult situations.

Functional assessment of ability to consent

(Ability to communicate a choice, understanding information relevant to the decision, retaining relevant information, manipulating information rationally, appreciating the situation and its consequences.)

Bill makes his choice not to undergo further dental treatment clear and is consistent in his view. Bill is reluctant to take part in any conversation related to his teeth, although clearly knows what dental treatment involves from his previous experience. Bill's last trip to the dentist resulted in complications and a lot of pain for Bill. This appears to have put him off attending the dentist again. Bill appears to see painkillers as helpful at the present time, not seeming aware of the long-term consequences of not having dental treatment. When shown pictures of teeth that have decayed and then fallen out Bill has appeared to take in the information. He will say that his teeth will fall out if he does not go to the dentist, but seems to see this as a good consequence as there will then be no further pain. Bill's view has not change with further information and discussion about his problem.

Bill continued to refuse dental treatment.

CASE VIGNETTE 2.

CAPACITY TO CONSENT TO A SEXUAL RELATIONSHIP

(Initial information for participants)

Wendy has been in a relationship with Mark for about a year. Mark is saying that he would like their relationship to become sexual and has been asking to stay in Wendy's room.

You have been asked to assess Wendy's capacity to consent to a sexual relationship.

APPENDIX 11.

CASE VIGNETTE 2. CAPACITY TO CONSENT TO A SEXUAL RELATIONSHIP

(Interviewer's details)

Wendy

Age

35

Brief history

Both Wendy and Mark have moderate learning disabilities. They have had a close relationship for a couple of years, perceiving themselves as boyfriend and girlfriend. Wendy has not been in a previous relationship. She is not on the Pill

Current circumstances

Both Wendy and Mark live in the same residential house with four other clients (which has waking night staff). They also attend the same day centre, although do different activities throughout the day generally meeting up during breaks. Their relationship is clearly held in high esteem by their friends and an important part of their respective identities and status.

Wendy lived with her parents until she was in her mid twenties before moving into her current home. Wendy continues to see her parents regularly.

Current problem/ Cause of concern

Mark is now saying that he wants to have sex with Wendy and says he may leave their relationship if this does not happen. Until now, staff have discouraged Mark from staying in Wendy's room, as they are unsure of what Wendy wants or her capacity to consent.

Wendy's relationship with Mark

Wendy and Mark appear to be close and in general spend a lot of time together. They are affectionate with one another kissing and cuddling appropriately. Both can be very caring and supportive of the other. Mark however is more dominant than Wendy and at times will use threats in order to get what he wants. Wendy will often do as he says and follow his lead, but sometimes can appear unhappy about this.

What does Wendy want?

When Mark asks Wendy to have sex with him she will say 'yes' to him. When asked by her parents, who disapprove of her relationship with Mark, Wendy will say 'no' she does not want sex with Mark.

Learning disability

Wendy has a moderate learning disability (exact IQ not known). In many ways, she can be very independent. She does not require help with personal care and for example is able to make a cup of tea, pour cereal for breakfast etc. However, Wendy is dependent on routine and does not cope well with change or new situations. Her communications skills are poor, she finds it particularly difficult to express what she wants or how she feels and is likely to say what she thinks others want to hear in order to please. Wendy's independence is enhanced by Mark who will take her to the corner shop and to see his/her parents etc. They know the bus routes to his/her parents

Functional assessment of ability to consent

(Ability to communicate a choice, understanding information relevant to the decision, retaining relevant information, manipulating information rationally, appreciating the situation and its consequences.)

Staff have talked to Wendy about her understanding of sex through the use of pictures and drawings. Wendy will say that people do it when they love each other. When asked what can happen when people have sex, she says a baby will grow. When asked what she wants (when Mark is not present) she says she sometimes wants to have sex with him, she loves him, she doesn't want him to leave her but doesn't want a baby. When asked what Mark would do if she did not want sex, she said he would probably go. Wendy's responses to these questions were consistent over time. Both Wendy and Mark were given more educational information about sex and contraception. Wendy then said, that 'yes' she wanted to have sex with Mark. When asked if she wanted him to stay over night in her room she said 'no'.

Not phobic about the idea of penetration as far as know

Mark

Age
38

Additional/ General information

Mark has a moderate learning disability (exact IQ not known). In general he is quite independent being able to take the bus to his parents, walk to the corner shop to buy snacks etc. He is able to make his feelings clearly known, but finds it difficult to cope when he cannot do what he wants finding it hard to take the view or needs of others into consideration. At these times, Mark can become frustrated and angry. Mark's parents are unconcerned about his relationship.

TEXT BOUND INTO THE SPINE

Interview 3: Psychologist

Vignette 1. Medical Intervention

PART 1.

- P 1 What level of learning disability has he got?
I 2 He has a moderate learning disability
P 3 How old is he?
I 4 58
P 5 OK... What sorts of supports does he need at the moment?
I 6 Umm, he lives in a residential house and there are staff there
7 24hours, umm, he can do most kind of basic everyday things, but
8 outside of the house he is not particularly independent.
P 9 Has he been... has he had any sort of psychometric testing done?
I 10 No...
P 11 So we are just guessing that he is moderate based on?
I 12 Based on his general abilities.
P 13 OK has he had medical treatment in the past?
I 14 He has had dental treatment in the past
P 15 Did he consent to that?
I 16 He went along with staff, um, quite happily and went through with
17 the treatment
P 18 OK do I need to make a note of the questions I am asking
I 19 If you want to
P 20 Does he understand the consequences of what will happen if he
21 doesn't get his teeth done?
I 22 He understands that his teeth will keep decaying and they may fall
23 out but he sees that as an OK consequence, its better than going to
24 the dentist
P 25 So he really quite phobic about the dentist is he, has he had a bad
26 experience with medics and doctors and stuff before?
I 27 It was very painful last he had a tooth out, last time it was very
28 painful.
P 29 OK and what he had a lot of aftercare problems, will he need a
30 general or a local anaesthetic
I 31 Umm, I think the dentist is probably thinking that he will need a
32 general anaesthetic this time
P 33 So Bill he thinks it is a reasonable consequence because he
34 doesn't like the dentist?
I 35 Yes... it's a better consequence than
P 36 Well I mean that's a decision that a lot of people without a
37 learning disability take. I'm forever trying to get my partner to the
38 dentist it's a nightmare..... I suspect that if its not life
39 threatening... so if he doesn't get the treatment then his teeth will
40 just decay and decay and decay and he will be in lots of pain and
41 stuff, but he is so phobic about the dentist he doesn't want to go
I 42 He is quite clear... I mean he will avoid talking about it but when
43 pushed he is quite clear that he doesn't want to go.

IQ

Level of Support needed

Past assess

Past medical treatment.

Past consent

Consequences if not treat

Reason why not want treat

What will treat. be.

Normalizing decision

all related to level of skills

Client's experience

Risk

Understand Client

Again Risk

Understand Client

right to

autonomy

Assessing situ
? of Cap - to
what

Life threatening
no treat
level of
seriousness

trying to find
other ways of
get him to go.

ass of C based
on understand of
consequences.

serious : :
to need to rush
treat - not about
child rights - but
Dogs paternalism

Make Scale I.D
LD & C.

g. skills impo

- P 1 So the only way to treat it is through removal?
- I 2 That's what it sounds like because he hasn't been to the dentist to
- 3 really check it out
- P 4 So I'm asked to assess his capacity?
- I 5 Umm...
- P 6 Quite frankly I would say that if he doesn't want it don't force it
- 7 on him. its not life threatening. he is making it quite clear because
- 8 a lot of adults make that decision. I mean obviously we would try
- 9 and talk to him about it, explore the fears he has got... I would
- 10 take him... it's not quite what you are asking is it... I would take
- 11 him to the dentist to show him around, introduce him and that sort
- 12 of stuff... I'd see if that would change his mind. But if he is
- 13 clearly able to see the consequences... how would I. how would
- 14 I... the only practical way to assess it is by verbal interview isn't
- 15 it there is no real sort of ... we know his level of learning
- 16 disability. I would try and make it clear that he understood what
- 17 the consequences would be to see if he could understand the
- 18 consequences of not getting his teeth done. I Imm it's
- 19 problematic though because we tend to do this all the time to
- 20 people without stopping to think.
- I 21 At the moment he is taking pain killers quite frequently
- P 22 I mean how frequently?
- I 23 Every other day
- P 24 Is he able to carry on with this does indefinitely?
- I 25 Umm. there is some concern about the long term consequences of
- 26 keen taking them
- P 27 I don't think we could force him to do it I think we just have to
- 28 wait until he teeth got so bad that the pain got more than the fear
- 29 of the dentist I'll ask you afterwards what other
- 30 people have said but it's not like he has got cancer or he needs
- 31 screening or something that's a bit different OK the only way I
- 32 would attempt to assess him would be to verbally interview him
- 33 and ask him to him see if he could understand what would happen
- 34 if he didn't get it done. if his mouth would get abscessed or
- 35 something like that, but if it wasn't life threatening then I would
- 36 leave it
- I 37 Alright, OK, that's fine.

PART 2.

- I 38 Umm, if we go back over the questions you asked, so you started
- 39 off with his learning disability... what made you start there
- P 40 That sort of gives you a base line level of what you are working
- 41 with... I would assume the more learning disabled he was the less
- 42 able he was to make this decision for himself. That he might not
- 43 be thinking cognitively that it might just be a stimulus response
- 44 thing the more disabled he was.
- I 45 And then you just asked about his age

level of
seriousness.

treatment

LD - abutments

Risk

level of
Risk

- When
make dec
for client

overall
level of
LD

Age.

P 1 Well if he was a child the rules are a bit different aren't they, the
2 rules are a bit different. you can iust sort of force a child to have
3 treatment without their consent if they are under 16.

I 4 And then we talked a bit more about his learning disability and his
5 actual abilities.

P 6 What did I ask I can't remember?

I 7 Umm. his abilities in the house what he actually...

P 8 Yeah, to me that would just give me a general idea of the level he

ask beyond L.D label

can + can't do

exercise choice

consent

9 was functioning at because I would assume, you know it is
10 difficult to. umm. it's s bit like this conversation that we are
11 having at the moment, you can assign a label and that but it is
12 often more useful to find out what they can and can't do for
13 themselves and see if he is exercising choice and consent in any
14 other areas of his life, if he is doing that responsibly.

I 15 Umm... and then we talked about the consequences and what he
16 understood by the consequences.

Seriousness of
Consequences

P 17 Umm, umm... I mean I, if he had like a big boil on his testicles
18 and it could be testicular cancer then that is quite different. but the
19 consequences, well what are the consequences of bad teeth it's not
20 life threatening, he is just going to be in a lot of pain and a lot of
21 adults without learning disabilities make exactly the same
22 decision, they don't do to the dentist. So I think the level of
23 consequences, the level of the impact of the consequences will
24 determine how insidiously you will seek the consent to get the
25 treatment done. If it is not life threatening like this then you
26 know...

normal response

I 27 And it sounds important not to be applying something to someone
28 with a learning disability that you wouldn't be applying to
29 someone else?

P 30 Well, yes absolutely it is his decision.

I 31 OK... umm

P 32 That might be a bit rational, but the pain will probably force him
33 to the dentist.

I 34 And then we talked briefly about pain killers

P 35 Well I just wondered if he was on high levels of paracetamol and
36 whether this was interfering with other medication he might be on.
37 I don't know if he is on anti-psychotics or antidepressants or
38 something, but if the painkillers were actually doing more damage
39 than the need for dental care then that's another matter, but if he is
40 on a safe level... you know patients are so dosed up on these toxic
41 drugs... you know what is a few paracetamol, if he wants to carry
42 on like that for a couple of months.

I 43 OK and your decision would be that you would kind of leave him
44 to...

P 45 I'd leave him.

leave him

? is this based
on capacity or
on ~~patient~~ profs. view.

look for ways
to say have to
have it done

Why should
or shouldn't
have done
not does, does
not have C of
C.

assumptions
Seriousness.

level of
Seriousness
based on.
- conseq
- risk

3

Vignette 2. Sexual Relationship

Psychol 3.

PART 1.

- I Umm, we'll go onto the second one.
- P Same questions really... the first thing is again is how disabled is Wendy?
- I Umm, she has a moderate learning disability and her IQ doesn't dictate that she can't have a sexual relationship
- P I'm a lot less liberal about sexual things because... OK who is Mark? Has he got a learning disability, is he a client, what's his level?
- I Mark is a client, again he has a moderate level of learning disability and they are two clients who live in the same house together.
- P Who is the more able one?
- I Umm Mark is slightly more able slightly more independent.
- P That is often... I would be very, very suspicious of this whole set up... often men, you often get the case of the man who is slightly more able and there is, is there any sort of coercion, has Wendy said she wants a sexual relationship?
- I Wendy is quite ambivalent. To her parents it's a no, to staff it is sometimes a yes and to Mark it is quite often a yes.
- P So, so, yeah so maybe he is pressurising her into it, how old is Wendy?
- I Wendy is 35
- P Umm... I'd get Wendy on her own for a start and try and get her away from Mark to talk to a female worker and see what, I suppose the obvious route is does she understand about the physical consequences of a sexual relationship, pregnancy, would she be able to care for a child if she became pregnant. I'd want to know that, does she understand how her body works about periods and menstruation. There is often a woeful lack of uh, level of ignorance, does she know about fertile periods and infertile periods, and mean how, I mean I'd try and understand how much she understood about her own physical processes, umm and then I would probably start asking her something about contraception and what she understood about that. I'd want to know whether she would be able to take contraception regularly and reliably. if she was safe enough for her to take the pill, I'd want to determine that, umm... I mean I'm very old fashioned about this.... I'd try and discourage it quite frankly.... I mean people have their urges the same as everyone else but the consequences are so horrific half the time you get these women having kids and getting them taken away from them. What does Mark understand?
- I If I were to say that at this stage the staff have taken each of them through the various basics of sex and they have understanding of that and that Wendy is saying that she will take the pill and the

LD.

men

LD.

equality
rela.

Coercion

Age

Sex knowl.

Convey for
people LD.

low + IQ

overall

level of

LD.

Relationship

choice

LD

abilities/
Skills

Risk

Role.
legislation

P

staff feel that she has some understanding of that and we working on those lines what would you kind of be looking at?

So staff said that she got some understanding, well I don't know if it is any of our business really then because if she is not legally below the level then I am not sure that she needs to get consent from staff. I don't actually think legally that it is any of staffs business what the two of them do. It is staff responsibility to make sure she is safe and practising safe sex with condoms and stuff but I actually think the question itself is a bit spurious if she is not below the legal limit, then you can't prevent her.

legal.
autonomy vs
protect.

I

What about the coercion factor?

P

Well this would be my concern, but even then, even if she was, I mean god how many women are coerced into having sex with their boyfriend you know, you don't have to have a learning disability for that to happen, umm... she is likely to be. I mean how likely are you to get an honest answer and I mean what else is she getting from Mark, I mean if she is getting attention, I mean it is a huge thing between learning disabled women to be able to have boyfriend and I know from research that people did in my year that having a baby is the ultimate status thing, that they are normal women. So she is likely to... I think it would be very hard to elicit whether or not she was being coerced, that is really going into some sort of deeper analytical type area and I don't think you can actually... I mean the fact that she is saying no to her parents and yes to Mark is probably evidence that she is, but then even if she was unless he was actually raping her then there is actually not a great deal that staff can do... do you see my point? So I actually don't think the question is relevant and I think this happens anyway. She has got a moderate learning disability. I think she has got the ability to consent to a sexual relationship what I think it really concerns me is the fact that Mark is more able and is probably using his male... his higher ability and his male sort of dominance type thing...

normalize
- compare
to general
popu

Coercion
normalize
Rela.

choice
right to
choose.

Coercion.

I

He is saying that if their relationship doesn't progress further then he would probably want it to end...

P

Well of course he is a typical bloke isn't he, he is thinking with his dick, I don't know whether you agree with me. Again what can you do there are loads of these sorts of packages, understanding my body and the sort of formal type stuff, but how useful they are... I think in real life terms they are not very useful, I think if she had a mild learning disability that would be different, but I think a moderate level of learning disability makes it harder, I was just reading a paper the other day about this bloke who umm, he was a keyworker, a member of staff and she was a client, did you read about it?

LD.
skills &
abilities

Sex inst.

I

No I didn't

P

I might be really useful for you, the judge actually said that she consented by her base animal instincts, that was how... they went right back to this victorian ruling and said that he didn't actually,

he got her pregnant and they were saying that it wasn't rape because she was submitting to her animal instincts. this was just about a couple of weeks ago. Ummm, I'm drifting off now, umm...

I So it sounds like you're kind of saying that you'd be looking at her understanding of the whole process and if you felt there was a reasonable understanding there, then the rest of the decision is actually hers.

Understand
= LD

P I think so, I'd have to, I think the only way, the only assessment you could do is understand the physicality of it and the consequences you can't really assess what is going on in her head in terms of male, female power relationships, higher, lower IQ power relationships, every relationship I have seen the man is always more able, it almost never happens the other way around, you know, the most we could do is check that she is having safe sex and she knew about using condoms and she would demand that he used a condom and that she was on the pill, that is about as much consent, about as much understanding that you could elicit from her, as much as you could quantify

Prof Role

assess risk then
decision
hers.

I Would there reach a point in those power dynamics where it would get to point where you would think, felt it was important not to let her umm have sex with him?

P How could you prevent it? I mean if she was clearly distressed by it, if she was crying and telling her keyworker that she didn't like what was happening, he was being rough with her or that he was forcing her to have sex with her more often then I think you could say that you could intervene. I think that there would have to be quite clear evidence that he was being abusive towards her. But you can't deny her the status of having a boyfriend or whatever... or even the human company, the sexual gratification.

Right to
Choose vs
right to
protec from
harm.

PART 2.

I OK going back over the questions again, umm you started off by asking what her learning disability was

P Yes, again I mean that's because of the law isn't it, because people of I don't know what the IO is that they deem you not too be able to give consnet. So I think the law is answering the question for us within the normal you know like a child under 16 can't give consent, you know if she is within the range of consnet then you have to assume that she can give consnet.

I And then you said, who is Mark

P Yeah, I mean, you know you need to check, it's like having a power imbalance adult, child; pupil teacher you need to work out whether the imbalance is so gross that it is obvious that she is not consenting that she is being coerced if Mark didn't have a learning disability if he was someone off the street that she had met somewhere, at the bus stop or something, that would be very different

law makes
decision
LD. overall.

Relationship
Coercion

Sexual
Rela.

Rela.
abuse

D. Legislation

Rela.

power imbalance

Coercion

APPENDIX 13.

TRANSCRIPT CODING

The initial codes in the first column correspond to the notes written in the left-hand margin of the transcript upon first reading. The emerging themes and ideas in the middle column correspond to the notes written in the right-hand column upon rereading the transcript. The final themes provided in the last column refer to the final theme classification given to the codes in the first column.

The analysis of the first two interview transcripts is included below. The analysis of vignette one and of vignette two is provided separately.

Vignette 1. Capacity to consent to treatment

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
IQ	Learning disability	Learning disability
Age	Background info	Understanding client's decision
Level of support needed	Learning disability	Learning disability
Past treatment	Trying to understand the situation	Understanding client's decision
Past consent	Trying to understand the situation	Learning disability
Client's understanding of consequences	Skills and abilities	Learning disability
Past experience of treatment	Reason not want treatment	Understanding client's decision
What treatment needed	Treatment needed	Seriousness of situation and intervention/ treatment
Normalise client's decision	Understanding the client	Understanding client's decision and rights of the Individual
Not life threatening	Level of risk	Seriousness of situation
Respect client's choice	Decision re capacity	Rights of the individual
Ways to help client	Support for client	Intervention/ treatment
Try to change client's mind	Client's choice	Intervention/ treatment & Protection from harm

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
Client's understand of consequences	Client's skills/ abilities	Learning disability
Problems assessing capacity	Assessing capacity	Learning disability
Can't force him, wait till more serious	Seriousness of situation	Protection from harm
If cancer it would be different	Level of risk	Protection from harm
More learning disabled less likely to have capacity	Learning disability	Learning disability
Decision = stimulus response	Trying to understand the situation	Understanding client's Decision
Force a child to have treatment not an adult	Finding reason client not have capacity	Protection from harm and understanding client's decision
What can client do/ not do	Client's skills/ abilities	Learning disability
Can client exercise choice in other areas of life	Client's skills/ abilities	Learning disability
Consequences determine when intervene	Level of risk	Rights of the individual vs protection from harm
Treat people with learning disabilities = to people without learning disability	Respect for client	Rights of the individual
Present and previous experience the dentist	Understanding the situation	Understanding client's decision
Clarifying actual problem	Understanding the situation	Seriousness of situation & Intervention/ treatment
Current symptoms	Seriousness	Seriousness of situation
Communication skills	Abilities	Learning disability
Teams knowledge of client	Understanding situation	Intervention/ treatment
Assessment already done?	Understanding situation	Intervention/ treatment
Participant's role	Professional role	Professional role
Client's mobility	Background info	Intervention/ treatment
Client's self care skills	General level of ability	Learning disability

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
Level of learning disability	Level of learning disability	Learning disability
Client's accommodation	Level of independence	Learning disability
Staff level of training	Not giving client correct info re treatment	Understanding client's decision
Age	Background information	Understanding client's Decision
History of dental care	Understanding situation	Understanding client's Decision & Intervention /treatment
Level of independence	General ability	Learning disability
Mental/physical health problems	Understanding situation	Understanding client's decision
Experience of other treatment	Client's knowledge	Understanding client's decision & Learning disability & Intervention /treatment
Medication client taking?	Possible complications	Seriousness of situation
Communication skills	General abilities	Learning disability
Not a consent issue	Intervention needed	Assessment of capacity Vs Intervention/ treatment
Client not saying yes due to lack of staff training	Client not informed	Understanding client's decision
Persuade client to agree by intervening	Intervene	Assessment of capacity Vs intervention/ treatment
Misdiagnoses of problem	Not issue of capacity	Understanding client's decision
Intervene to help client face his fears	Treatment approach	Understanding client's decision
Seek medical opinion on need for treatment	Seriousness/risk	Seriousness of the situation
What I do is based on my view of client's needs	Paternalism	Protection from harm

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
Treatment not essential	Not view as serious	Seriousness of the situation
I decide what best for him	Best interests	Protection from harm
If client does not agree to treatment then it becomes an issue of consent	Protection from harm	Protection from harm
Why isn't he accepting treatment	Understanding client's decision	Understanding client's decision
Assessment by SLT, Psychologist	Professional role	Professional role
Client's understanding	Client's abilities	Learning disability
Respect for client's wish but he needs treatment	Balance between rights and protection	Rights of the individual vs protection from harm
Not able to give informed consent no knowledge of benefits	Not informed	Understanding client's decision
Concern/ criticism of previous care	Reason client not consent	Understanding client's decision
Immediate or long term problem	Problem severity	Seriousness of the situation
What is stopping client agree to treatment	Reason for client's decision	Understanding client's decision
Subjective view of client's needs	Misdiagnoses	Understanding client's decision
More detail of learning disability	Specific skills and abilities	Learning disability
Client's ability to understand and make choices	General abilities	Learning disability
Level of independence	Level of learning disability	Learning disability
Staff level of training indicates client's level of ability	Level of learning disability	Learning disability
Client's health	Need for treatment	Seriousness of the situation
Mental and physical health problems reduce capacity	Reasons not got capacity	Understanding client's decision
Uncertainty about role	Professional responsibility	Professional role

Vignette 2. Capacity to consent to a sexual relationship

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
Accommodation	Independence	Learning disability
House rules re: sexual relationships	Protection	Protection from Harm
Other professionals involved	Gaining information	Professional role
Staff support available	To support client	Intervention/treatment
What is the client's view	Understanding client choice	Understanding the current situation
Views of others	Influence on client	Understanding the current situation
Understanding of sexual relationships	Knowledge/ability	Learning disability
How client feels about partner	Relationship/choice	Understanding the current situation
Time alone together	Relationship/risk	Understanding the current situation
Client's level of independence	Level of learning disability	Learning disability
What do client and partner do together	Relationship	Understanding the current situation
Partner's level of sexual knowledge	Level of ability	Learning disability
Possible already had sex?	Risk of pregnancy etc.	Understanding the current situation & protection from harm
Views of others	Influence of others	Understanding the current situation
Age of clients	Legislation	Rights of the individual
How making choice known	Skills and abilities	Learning disability
Being pushed into relationship by partner	Coercion/dynamics of relationship	Understanding the current situation
Can she stand up to him	Personality characteristics	Understanding the current situation
Intellectual ability	Level of learning disability	Learning disability

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
How is she coping with his request	Personality characteristics	Understanding the current situation
Level of learning disability both clients	Level of abilities	Learning disability
Differences in level of abilities	Power/risk	Understanding the current situation
Past relationships	Experience	Learning disability
Past sex education	Knowledge	Learning disability
Client's vulnerability	Personality characteristics	Understanding the current situation
Partner abusive	Partner's personality	Understanding the current situation
Partner's history of relationships	Risk factors/sexual knowledge	Understanding the current situation & Learning disability
Mental & physical health problems	Other problems affecting capacity	Understanding the current situation
Ability to understand process of sex	Level of ability	Learning disability
Not under any pressure	Dynamics of the relationship	Understanding the current situation
Needs education before able to consent	Not informed	Learning disability
Client's level of assertiveness	Skills/personality	Understanding the current situation
Professional aim to keep her safe	Protection	Protection from harm
How client deal with conflict	Skills/need for protection	Understanding the current situation & Protection from harm
If limited knowledge i.e. of pregnancy then at risk	Level of knowledge/protection	Learning disability & Protection from harm
Sex education done by nurse	Professional role	Professional role
Level of understanding of sex needed	Functional abilities/level of knowledge	Learning disability

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
Permanency of relationship	Relationship	Understanding the current situation
Level of violence/coercion	Relationship dynamics	Understanding the current situation
Duty to support client no matter what parents think	Client's rights/professional role	Rights of the individual
Client has right to live life the way they want	Client's rights	Rights of the client
Rules in house make things safe	Need to protect	Protection from harm
Care manager knowledge of rights of client	Professional role	Professional role
Opportunities for time alone – risk	Risk	Protection from harm
Vulnerability – level of support needed	Support/intervene/protect	Intervention/ treatment & Protection from harm
Partner's support of client's choice	Dynamics of relationship	Understanding the current situation
Legislation re age	Client's rights	Rights of the individual
What support client need and how best to offer it	Support/intervention	Intervention/ treatment
Understanding client's ambivalence	Client choice	Understanding the current situation
Mental health difficulties might limit capacity	factors affecting capacity/client characteristics	Understanding the current situation
Never want to work in isolation – miss something important	Multidisciplinary input	Professional role
Difficulties with these kinds of judgements	Uncomfortableness	Assessment of capacity vs Intervention/ treatment & Rights of the client vs Protection from harm
Not just can they or can't they but what support need	Aims of intervention	Assessment of capacity vs Intervention/ treatment
Not an issue of consent – just needs support	Intervention/support	Intervention/ treatment

<u>Initial codes</u>	<u>Emerging themes/ideas</u>	<u>Final themes</u>
Both clients level of learning disability	Level of ability	Learning disability
Concern about sexual relationship	Risk/protection	Protection from harm
Equality of relationship	Dynamics of relationship	Understanding the current situation
Differences in ability levels	Relationship/power imbalance	Understanding the current situation
Ages	Background information/experience	Understanding the current situation
Sexual knowledge	Knowledge and ability	Learning disability
Knowledge of risks and need for precautions	Knowledge and ability	Learning disability
Consequences of children for people with learning disabilities	Risks involved/distress	Protection from harm
Learning disabilities and legislation	Client's rights	Rights of the individual
What sort of relationship	Relationship dynamics	Understanding the current situation
Coercion/dominance of partner	Partner's characteristics	Understanding the current situation
Partner's sexual knowledge	Level of ability	Learning disability
Looking for a reasonable understanding of the whole process	Level of ability	Learning disability
Power in the relationship	Relationship dynamics	Understanding the current situation
Signs of distress/abuse	Relationship problems	Understanding the current situation
Law and sexual relationships	Client's rights	Rights of the individual
Development of their relationship – length of time	Relationship development	Understanding the current situation
Meaningfulness of relationship	Relationship development	Understanding the current situation
Age and legislation	Client's rights	Rights of the individual

Initial codes → **Emerging themes/ideas** → **Final themes**

Trauma of not being able to keep baby if gets pregnant	Need to protect/look out for client	Protection from harm
Feel women with learning disabilities are used by men	Inequality of relationship	Protection from harm
Get the community nurse to support client provide education	Roles of different professions	Professional role

APPENDIX 14.

RESEARCH DIARY

Late March 1999

Looking for a dissertation idea ...

Had kept in mind a teaching session by Katy Arscott (Tizard Centre) where she talked about people with learning disabilities and issues of capacity to consent. I had become interested in the rights of people with learning disabilities through my work, before training, with a self-advocacy group. The right to make decisions about one's life was often on my mind during this time. Thinking about this again now, questions about the massive decisions carers/professionals are often faced with when thinking about a person's competence and the importance and effect such decisions can have, are raised for me. I'm also thinking about how often such decisions about a person's capacity to consent are made all too quickly or not thought about because it is assumed the person does not have capacity to consent. I'm left thinking about how difficult these decisions are to make, both practically and emotionally.

Thinking about taking this further, what is it I want to ask questions about? I'm initially interested in decision-making in teams and the many decisions which are not clear cut - a person does or doesn't have capacity, how they grapple with moral decisions that can permanently affect people's lives. How do professional's own beliefs about right and wrong affect the process? Thinking about the uncomfortableness in professionals that these decisions often evoke, the confusion in the law - what decision should be made? Katy in her teaching made some sense of this, as if it were clear (Katy predominantly talked about the functional approach to determining capacity to consent and how to assess this). I remember at the time feeling relieved by this, but then as I think about it now feeling more uncomfortable because it doesn't feel quite this straightforward.

April 1999

Looking at the literature...

Historically a lack of recognition of people with learning disabilities, they don't make decisions affecting their lives. Struck by the parental nature of professional care- in practice is this still the case? As I read I feel annoyed at the way people with learning disabilities are viewed. The dissertation becomes more personal as I think about this and the lives of people I have worked with and the decisions that have been made for them about their lives.

I'm reading about the law in this area. My reading and thinking becomes wider, looking at capacity issues in relation to older adults and people with severe mental illness. I'm struck by the lack of definition within the law; the openness for interpretation. Again, I come to thinking about the responsibility of the professional in making these decisions and the lack of support provided by either the literature or the law.

I think about decision-making in practice. The use of the available literature; how approaches to determining capacity are applied in practice. I think about the interplay between theory, clinical practice and the role of professional judgement. Decisions about capacity thus become more complex than the literature suggests - the research question becomes clearer 'how do professionals make decisions related to capacity to consent in practice?' Looking again at the capacity literature there are numerous acknowledgements of the difficulties in applying theory to practice but nothing which explores this in any depth.

May 1999

How can I best answer the question 'how do professionals make decisions related to capacity to consent in practice?' I arrange meetings with people to help me think about this.

6th May 1999

Meeting with Tony – began to explore the possibilities of interviewing teams, asking them about a case in their own clinical practice where there have been issues around capacity to consent or presenting them with vignettes and asking them to decide. Is team decision making the best approach? To give a team a decision-making task, would this answer my question would it be possible in practice? It would tell me how they made the decision but maybe not enough about their reasoning, would it capture the complexity of the process? Also thinking about group effects on this process. I come away thinking that team processes and dynamics may affect the decision that I'm interested in too much – I'm not necessarily interested in how teams work together in making this decision. Need to rethink a bit.

13th May 1999

Meeting with Katy Arscott – Katy suggested thinking quantitatively about the questions that I'm asking, to do it by questionnaire but this doesn't seem to capture the essence of the decision making task and would in some way mean I make assumptions about how it is done. I think I'm more interested in thinking about it as it is happening – need a methodology which is more alive. What would a qualitative methodology capture that a quantitative methodology wouldn't and vice versa? Which best fits the questions I am asking. Begin to think about my question about decision-making in practice, need to expand on the limited amount known rather than ask questions or test out things already known. So far, much of the research in this area has been academic where models have been proposed; I'm interested in whether these reflect what is happening in practice. Thinking about what makes me interested in the perspective of the professional. I think it is because this is where my experience lies and in line with this its importance, given its direct daily impact on the welfare of client's with learning disabilities.

Decide to interview individuals from different professional groups because this reflects practice. Decisions related to capacity to consent rarely made by one professional group – needing to reflect practice as much as possible. So how do I uncover the complexity of the decision-making task, but keep it possible and realistic? Search for ways of achieving this. Keep reading. Explore decision-making in occupational psychology. Find an article in the Psychologist looking at the applicability of methods used to explore expert systems to clinical psychology. Think I have found a methodology that meets the needs of the research - question asking and verbal protocol analysis.

Proposal has begun to flow.

May 25th 1999

Finding a supervisor was straightforward. Someone who would help me keep focused, who wouldn't let me down and would keep me thinking and also had an interest in this field.

First meeting with supervisor – leaves me feeling positive.

May 28th 1999

Proposal submitted.

June 1999

Feedback from external examiner – critical have I thought about the differences between professionals and the way they might approach this task. Is content analysis the best method of analysis? Leaves me feeling defensive.

July – August 1999

The three services I approached were all very interested. First need to get ethics approval

Late August – Early September 1999

Local Research Ethics Committees. No major ethical concerns so breezed through ethics committees. All going well – everything going faster than can keep up with. Need to slow down as other deadlines. This gap has allowed me to reflect and think more clearly about the issues.

September 1999

Meeting with Len Rowland – all seems to be well with the research design, but what about the different decision-making styles of different professionals. This needs to be acknowledged within the research design. For example, the biases that this may present, different ways in which managers and clinicians, medical and non-medical staff may approach the problem. (There is literature that I haven't thought about – oh no! – back to searching and reading).

Small problem, feels like a huge crisis, why does it matter? I don't think there will be differences I think for all it will be a complex moral decision with no easy answers. What is qualitative research trying to do? I'm not looking at differences but exploring the way in which professionals approach this task, in a way that most reflects practice. Interviewing only one professional group would be limiting.

Read the literature – not sure of its relevance to my research. However it makes me think more about all the factors and biases that will be affecting the way in which each professional makes decisions.

The breadth of my reading has increased through this process. Topics like judgement, decision-making, ethical decision-making in general are coming up and being explored.

October 22nd 1999

Meet with Jan (back-up supervisor) to think about how to acknowledge the differences between professionals within the methodology. Jan suggests possibly adding a number of questions to the end of the interview with regards to where professionals see themselves in terms of medical – non-medical, clinician – manager. Think about this further and decide that this is moving away from what I am looking at and the studies qualitative design.

Arrange to talk further with my supervisor – need help clarifying my thoughts

18th November 1999

Meet with supervisor to discuss new ideas. Chance to think out loud about what I am doing.

Decide to address the issue of differences between professionals in three ways. To add a research question 'Are decisions made relating to capacity to consent, made differently by different professional groups?' And to increase the number of professionals I will interview so that differences, if there are any, are likely to be more explicit and only interview professionals working clinically in this field.

Again I feel more positive about the study.

December 1999

Feedback from Salomons Ethics committee more thorough. Need to clarify the way in which the vignettes were written. Again the feedback is making me think about the most appropriate method of analysis to use.

Vignette details – what is it that I want to gain from giving participants vignettes? There needs to be opportunity for participants to use any modal or approach to determining capacity to consent, therefore the information they are initially given needs to be very brief so as not to influence where they may start. Not want to influence the approach they may take. Should the clients in the vignettes be male or female, should the choices the clients' are making be what most people would choose or not? What degree of risk should be reflected in the vignettes i.e. should the client's choice in the treatment vignette be life threatening or not, or in vignette two should the client be at serious risk of abuse? Decide to take a 'middle of the road approach'. No extremes which makes decision-making more difficult, therefore hopefully pulling out the full range of factors considered when making this kind of decision. Try to take opposites in each of the two vignettes so that if there are any differences in the way that this affects decision-making this will be apparent.

January 2000

Pilot methodology. Disappointment it didn't work as well as hoped. The idea of obtaining a verbal protocol from the participant through asking them to think aloud was problematic and interrupted the flow of the interview.

Back to the drawing board.

Whilst initially this felt disappointing the new methodology feels more positive and an improvement on the first design. Send it to supervisors for comments. Comments positive.

January 25th 2000

Piloting of the new methodology has resulted in a few changes to the initial vignette information given to participants and to the questionnaire. Think about including more questions at the end of the interview about how the participant felt making these decisions. However, the interview took a long time, so decide it would become unmanageable to make it longer. Any more questions will have to be left for another research project.

Wondering whether the vignettes present a case which is challenging enough. At the same time wondering how much professionals will know or won't know about capacity to consent. Have I got it all wrong or right?

Feeling anxious about starting interviews.

February 1st 2000

Interview with first psychiatrist– relief

Went well, participant had a lot to say interview was very long. Ended because the participant needed to go to another appointment. Participant talked about capacity and best interests. What was in the client's best interests and the need to intervene seemed to override capacity. Left with a strong sense of paternalism in the way the assessment was approached.

February 14th 2000

Meeting with supervisor, to talk about first interview. Felt positive about the interview, how it went, the kind of information that came out of it. No changes to interview design needed.

February 15th 2000

Interview with first care manager. Participant unsure of what they had to offer. They said that in practice they were unlikely to get involved until something had gone wrong or happened already. However, took a coherent approach to the assessment and very thoughtful about difficulties the assessment presented.

February 17th 2000

Interview with first psychologist – much more functional in their approach. Excellent interview. However got home to find it had not been recorded – nothing to transcribe. The interview was unusable very, very frustrating, incredibly annoyed with myself.

February 24th 2000

Interview with second psychologist. Least experienced of participants so far, succinct and clear. Much shorter interview although similar themes emerging.

March 2nd 2000

Interview with third psychologist. Very experienced and very thoughtful about professional role and the subjectivity with which decisions are often made. However, the interview format felt restrictive, tried to keep it broad enough to allow the participant's thoughts to be encompassed within the interview. I think this worked OK. Participant wanted to talk about all the difficulties of establishing capacity rather than how they might approach it given the case vignette presented to them. Left me thinking about the role of clinical experience on how capacity is determined.

Have had difficulty arranging to meet nurses, unsure of their interest in participating. However, presented my study to them today at their team meeting. They grilled me on my interest in capacity to consent and my experience in learning disabilities, but were really keen to participate, not able to interview all those who were interested. Expect some interesting interviews.

March 8th – 16th 2000

Involved in the selection interviews at Salomons for the next intake of trainees. Dissertation on hold, keep trying to make phone calls to arrange further interviews. Begin to feel like I'm hassling people to call me back.

March 20th 2000

Have a week of interviews planned. Week starts with briefcase being stolen from my house. Diary, tape recorder and dissertation materials gone! Very stressful next two days, can't do anything without my diary. Have to cancel interviews. Frustrated, stressful feeling low and fed up. Receive call from very nice man saying he has found my case – everything regarding my dissertation still inside, yeah! Happy again.

March 22nd 2000

Three interviews with nurses. Long day but interesting doing them all together. All very different but similar themes emerging, although nurses seem to be clear in their role in this area i.e. they do direct work assessing or intervening, the assessment of cognitive abilities would be down to other

professionals. Some nurses clearer than others about the actual skills or abilities that should be assessed.

March 23rd 2000

Third nurse interviewed. Good interesting, full interview, again similar ideas emerging.

March 24th 2000

Fourth psychologist interview. Participant placed lot of stress on what other professionals have to offer and that psychologists don't have all the answers. Whilst all professionals so far have considered the client's skills and abilities in the vignettes it seems that there is no coherent way of doing this, skills assessed directly with regard to the task being considered or indirectly by looking at the client's skills in other areas of their life.

Having difficulty contacting psychiatrists. Concerned will not be able to interview enough without going to another service and hence another ethics committee. Discuss with research group. Decide that interviewing four rather than five psychiatrists will be a limitation but not a disaster, therefore decide not to approach another service.

March 27th 2000

Interview fifth psychologist. There appear to be two questions that participants ask when presented with this problem. The first is can this situation be addressed in another way i.e. through treatment or intervention. The second is, what is the client's capacity to consent. Some Participants are more explicit about this than others.

Have begun to write the introduction. Try to tell the story of the research, why I came to ask the research questions I did. Finding it much more difficult than I anticipated. Spending a lot of time trying to write a coherent account of where we are at in terms of our understanding of capacity to consent. Thinking more about the process of judgement and decision-making in general, what will my research draw out?

Need to think about beginning to analyse the results.

March 28th 2000

Last interview with psychologist. Makes me think about theoretical orientation and the way the participant views the problems being presented, particularly in the way that they try to understand the problem and client's choice. However, so far this does not appear to be particularly explicit in the interviews.

Have not yet booked all my interviews – finding this very stressful not feeling within my control.

April 6th 2000

Two more interviews. Last nurse and second psychiatrist. Both interviews were difficult in that the professionals found it quite difficult to know how to approach the problem. Leaving me feeling that the interviews had not accessed what I wanted to get at. However, both understood the interview method I was using and were able to ask questions about the vignettes. So what was the problem? The nurse didn't consider either case to be issues of capacity to consent. This appeared to be because they weren't serious or risky enough and that other ways of approaching the problem had yet to be tried. Assessing capacity to consent being the last resort. Thus the right of the client to choose was essentially ignored. Interviews left me feeling cynical about the understanding of professionals in this area. The rights of

the individual were ignored, the professional appearing to miss the point. On the other hand everything that participants have talked about doing has been in the client's best interests – participants do what they think is best. Not able to put aside need to care or do something other than just respect wishes.

April 10th 2000

Away on a course at the Tavistock for a week.

April 13th 2000

Interviews with two care managers. Both very keen although unsure of how much help they might be able to offer 'you can write what I know about consent on the back of a postage stamp'. Although both had experience of capacity issues with clients. Interviews turned out to be very interesting.

Left thinking about 'duty of care' and capacity to consent. First, try to help the client make a positive decision. When not able to do this and problem is complex then it becomes an issue of capacity. Duty of care however outweighs the clients right, even if they have the capacity, to choose. Whilst I understand where these participants are coming from in terms of needing to do what is in the client's best interests, this goes against the rights of the client.

Feel like I need to know more about the duty of care and best interests. Go back to the literature.

Thinking about the interviews in general. Almost as if professionals in tackling the first vignette take the approach of trying to disprove capacity whilst in the second try to prove capacity. What is this about? Is it related to the client's choice or the risk the situation poses?

April 20th 2000

Interview with psychiatrist. Good interview

April 26th 2000

Interview with fourth care manager and last psychiatrist. Interviews continue to reflect similar themes but to different degrees. Feel happy with the number of interviews I have done in that I feel like I have an extensive range of the possible ways in which professionals may approach assessing capacity to consent in these case vignettes. Few new ideas are emerging.

May 4th 2000

Last interview with care manger. Interviews complete. Now have to think about analysis. Looking at the transcripts the amount of information feels vast.

May 16th 2000

Meeting with supervisor to talk about first stages of analysis. Sometimes feel very positive about the study and at other times think about its usefulness. However, from one of the services I learn that following my interviews, a series of meetings have been set up to think about their capacity to consent policy. This leaves me feeling good.

Think about how to make the analysis manageable. Keep reading Smith et al. (1999) article, try to keep things logical. Break the analysis down by separating into the two vignettes – analyse separately. Break it down by initially looking at one interview from each profession first. Begin to see familiar themes coming up across vignettes.

End of May 2000

Analysis is beginning to find a structure. Ideas and themes coming into my head quicker than I can work through all of the nineteen vignettes. Slow myself down, draw diagrams. Must keep myself grounded in the data and not get lost in my own interpretation of what I think is happening.

Writing up the results. They seem interesting, try different ways of presenting to find what makes most sense. At some points feel very anxious, panicky, feeling like I'm just never going to get it done. Other times feel more in control

June 9th 2000

Meeting with supervisor. Helps with anxiety levels to know that someone else thinks they are good results, interesting findings. Sometimes it feels like I've read through the transcripts so much that I can no longer view them objectively anymore.

I am going to do the changes to the results, send them to my supervisor and then leave then for a week. Next I think I'll go back and fill in the gaps which I left in the introduction and method.

June 23rd 2000

A birth and a death in the family. Brakes my flow. Hard to think about dissertation at the moment.

June 26th 2000

Changes to results made – feeling happy with them. Send copy of the results to all participants for their feedback. Everything takes longer than I expect at the moment. Have to think about inter-rater reliability, however this doesn't feel like the most helpful way of looking at the reliability of the findings, although it is only one way I will use to look at the study's reliability. What I want to do is go through with someone exactly what I have done, the process of analysis, how the themes emerged, why I interpreted things the way I did etc. Do I need to do this?

Almost everything done except the discussion. Feels like the last big pull on my energy. Must start it.

26th June 2000

Dear

**RE: RESEARCH PROJECT: DETERMINING CAPACITY TO CONSENT IN PEOPLE
WITH LEARNING DISABILITIES**

I am writing with regards to the findings of my study looking at how professionals determine capacity to consent in people with learning disabilities. You may remember that I said I would like to send back to participants the studies findings for comments.

I have now finished analysing the interviews and would very much appreciate your views on the results, which I have attached. I would be particularly interested in your views with regards to the following:

- 1) The findings of the study and the degree to which you feel they reflect how capacity to consent is determined in practice. I would be interested in both your comments in general and concerning any specific aspects of the findings.
- 2) The overall approach I used to assess how professionals determine capacity to consent in people with learning disabilities. (To jog your memory, I first gave you a small amount of information about a case vignette. I then asked you to ask questions about the case after which we went back over the questions you asked, thinking about your reasoning behind asking them).

I would really appreciate any comments you may have. Asking participants to look at the study's findings is one way of assessing their reliability and validity in qualitative research and hence adds to the study's credibility. If you do have the time to read through the findings and make any comments it would be helpful if they could be returned within two weeks, that is by 11th July 2000. I have enclosed an SAE for your reply.

With many thanks for your time and help,

Yours sincerely,

Katie Bourne
Psychologist in Clinical Training